National Library
of Canada

Canadian Theses Service

Ottawa, Canada
K1A 0N4

Bibliothèque nationale
du Canada

Services des thèses canadiennes

CANADIAN THESES

THÈSES CANADIENNES

NOTICE

The quality of this microfiche is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Previously copyrighted materials (journal articles, published tests, etc.) are not filmed.

Reproduction in full or in part of this film is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30.

AVIS

La qualité de cette microfiche dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

Les documents qui font déjà l'objet d'un droit d'auteur (articles de revue, examens publiés, etc.) ne sont pas microfilmés.

La reproduction, même partielle, de ce microfilm est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30.

THIS DISSERTATION
HAS BEEN MICROFILMED
EXACTLY AS RECEIVED

LA THÈSE A ÉTÉ
MICROFILMÉE TELLE QUE
NOUS L'AVONS REÇUE

NL-339 (r.86/06)

Canada

THE UNIVERSITY OF ALBERTA

A Study of a Self Help Group for Head Injured Persons and Their Families

by

(C) Terry Karpman

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE
OF
Doctor of Philosophy
IN
Counselling Psychology

Department of Educational Psychology
University of Alberta
Spring, 1986

Permission has been granted to the National Library of Canada to microfilm this thesis and to lend or sell copies of the film.

The author (copyright owner) has reserved other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without his/her written permission.

L'autorisation a été accordée à la Bibliothèque nationale du Canada de microfilmer cette thèse et de prêter ou de vendre des exemplaires du film.

L'auteur (titulaire du droit d'auteur) se réserve les autres droits de publication; ni la thèse ni de longs extraits de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation écrite.

ISBN 0-315-30328-X

THE UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR Terry Karpman

TITLE OF THESIS A Study of a Self Help Group for Head Injured Persons and Their Families

DEGREE FOR WHICH THESIS WAS PRESENTED Doctor of Philosophy

YEAR THIS DEGREE GRANTED Spring, 1986

Permission is hereby granted to THE UNIVERSITY OF ALBERTA LIBRARY to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only.

The author reserves other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

(SIGNED) Terry Karpman

PERMANENT ADDRESS:

556 Saddleback Rd

Edmonton, alberta

T6J 4Z3

DATED March 10, 1986

THE UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled A Study of a Self Help Group for Head Injured Persons and Their Families submitted by Terry Karpman in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Counselling Psychology.

J.G. Paterson

Supervisor

J.W. Vargo

External Examiner

Date. March 10, 1986

Abstract

The present study examined a self-help group comprised of families who are learning to deal with the day to day living following traumatic head injury in one of its members. The injured individual goes through a wide variety of personality, emotional, and behavioral changes. These changes directly effect the family and other relations. They need to adapt themselves and readjust to their new circumstances as they attempt to manage and maintain a healthy lifestyle.

One intervention that can facilitate recovery and the rehabilitation process is the involvement with a self-help group. Families as well as the injured individuals can share common experiences with each other, provide support, information, understanding, and encouragement. Consequently, managing a unique and often confusing disability can be facilitated.

Through participant observation and interview procedures, such a group was studied over an eight month period. Stake's (1967) model of group evaluation provided the basis for the analysis. The researcher attended group meetings and participated in community public awareness events. As well, family members and initial founders of the group were interviewed. It was anticipated that this would provide the opportunity to gain a good understanding of the group's practices and ongoing process. Via this exploratory study, a number of hypotheses were then formulated.

The descriptive results clearly revealed the reasons behind the need to initiate this group. It was indicated that the primary reason for beginning the group was support. There were a variety of secondary needs including increased public awareness, and the desire to obtain facilities necessary for the rehabilitation of brain injured persons. Active members felt strongly about getting their needs met in terms of giving and getting support, feeling a sense of pride and accomplishment with the success of the group, and having a centralized place to go to for information.

Three theories of recovery are described with particular attention paid to the theory of functional adaptation. Family members of the self-help group can utilize the ideas presented in functional adaptation with the goal of amelioration in mind. This type of intervention has the most potential and allows family members to get actively involved in the injured individual's rehabilitation process. In addition, recommendations for further research, and implications for rehabilitation and counselling are provided.

Acknowledgements

I would like to express my sincere appreciation to Dr. John Paterson, my chairman, for his invaluable guidance and direction on my dissertation, and for his constant encouragement and support throughout my graduate program.

To Dr. Henry Janzen and Dr. Jim Vargo, my supervisory committee, thank-you for your constant feedback and suggestions, and for your enthusiasm throughout this project.

To my committee members, Dr. Len Stewin and Dr. Lorraine Wilgosh, thank-you for your helpful comments and advice.

To Dr. Lee Handy, I appreciated your willingness to travel up from Calgary, and for your helpful suggestions.

Thank-you, Sandi Wolfe, who sparked my interest and invlovement in the area of head injury.

Special thanks is extended to the members of NABIIS, past and present, who were so willing to participate, to give their time, and share their experiences. Without them, this project would not have been possible.

Most important of all, to my husband, Shelby, thanks for always being there and for your constant support and encouragement throughout the years I spent as a graduate student.

In addition, I would like to thank Western Industrial Research and Training Centre, and Steve Dennis, for their funding and particular interest in this study.

Table of Contents

Chapter Page

I. Introduction 1
Background to the Problem 1
Purpose of the Study 5
Significance 8
Definitions 9
Overview 10
II. Review of the Literature 11
A. Head Injury 11
Victim's Characteristics 13
Family Characteristics 16
Summary 19
B. Self-help Groups 20
Definition and Typology 20
Professional Relations 29
Limitations and Potential Dangers 32
Summary 34
C. Group Structure and Process 35
Group Performance 37
Cohesiveness 41
Leadership 43
Summary 46
III. Methodology 47
A. Theoretical Underpinnings 47
B. Sample 50
C. Procedures 53

D. Data Analysis 55

E. Interview Schedule 57

IV. Results and Discussion 58

A. Intent 58

B. Observations 66

C. Contributions to the Literature 76

V. Conclusions and Implications 78

A. Intent versus Observations 85

B. Professional Involvement 87

C. Recommendations 88

D. Limitations 91

E. Implications for Rehabilitation and Counselling ..91

F. Suggestions for Further Research 93

VI. Referencs 94

Appendix A 105

Appendix B 106

Appendix C 109

Appendix D 110

Appendix E 131

I. Introduction

Background to the Problem

The consequences of a brain injury have been well documented throughout the literature (Cartlidge & Shaw, 1981; Jennett & Teasdale, 1981; Rosenthal, Griffith, Bond, & Miller, 1983). The idea that a traumatic head injury results in diffuse brain damage causing physical as well as psychological and psychosocial difficulties is now widely accepted. Individuals suffering from an injury exhibit many noticeable changes in their memory, language, personality, emotions, and behaviors. These changes persist and are the major factors contributing to stress for the individual and family members. They are all faced with dealing with mental sequelae inherent in the injury and with the challenge of regaining a productive and suitable lifestyle.

The uniqueness of the puzzle associated with head injury is best illustrated by the following quote.

> If head injured adults experienced severe though predictable deficits-as do patients with cerebral palsy-or only significant mental impairment-similar to that found in mental retardation-then there would be little difficulty encountered working through these problems in a traditional manner. However, head injury yields an unpredictable mixed array of deficits, and there is no way to

> predict the types of functional limitations that might result from a given injury (McNeny, 1983, p. 153).

Behavioral manifestations, in particular, are the most difficult to understand, predict and treat, of all the disorders that accompany traumatic head injury. Families can often cope with physical disability to a remarkable extent, but severe behavioral abnormality is liable to stretch them beyond endurance (Cartlidge & Shaw, 1981). As well, patients tend to exhibit a denial of the consequences of the disability which further interferes with the adjustment process.

The rebuilding of life after psychic shock is an active process that involves one's whole world, particularly within the family unit. Bond and Brooks (1976) indicated that the burden of caring for the patient, which entails long term management, falls on the family. As families are crucial to the patient's recovery, they need support and encouragement to withstand the stresses they incur. Their reaction plays a major part in the adaptation of the injured person (Walker, 1972), and their support promotes a positive outcome in rehabilitation (Bishop, Epstein, & Baldwin, 1981). Families require assistance if they are to function as a positive and effective influence on the patient's recovery process.

Changes in the injured individual affect family life considerably. For example, the presence of an irritable, mentally slow, demanding, and perhaps aggressive person who cannot be left alone except for a short time, curbs freedom drastically. As a result, family members feel trapped at home and socially isolated. Consequently, relatives may feel hostile and resentful toward the patient, then they may experience guilt feelings for having negative feelings about someone who is disabled (Rosenthal et. al., 1983).

The need for mutual support among family members, exchanging information and insights, and sharing burdens, problems and solutions is becoming increasingly apparent (Newcomb, 1982). In a study on relatives of people with Alzheimer's disease (Lazarus, Stafford, Cooper, Cohler, & Dysken, 1981), four themes emerged from group meetings. The first theme was that relatives had expectations for magical recovery rather than a realistic acceptance of the disability. The need is to provide realistic expectations regarding the course of the illness. The second theme was learning to cope with the afflicted relative. The third was the attitude toward health professionals, and the fourth was the feelings about the discussion group and its termination. The group leaders concluded that the group served a valuable educational and supportive role for relatives. By sharing common experiences and feelings, it relieved some of the isolation and loneliness that relatives of brain damaged patients often experience. Relatives who participated in the group became less absorbed with their family. New ways of communicating with patients contributed to feeling greater control over their own lives.

A support group for families following the head injury provides for the opportunity to inform members about the injury and its sequelae. Exposure to others undergoing similar experiences can help families gain a better understanding of the problems. They can exchange ideas about coping aids and managing home behavior. As well, one needs to find a balance in expectations of the patient's capabilities, thereby encouraging the patient's independence as much as possible (Mauss-Clum & Ryan, 1981). The group may assist the family and patient in re-establishing a role consistent with the pre-injury family model, aiding family members in understanding the nature of the patient's deficits and methods of alleviating potential conflicts within family interactions, and providing a supportive milieu where the patient may regain self esteem and the ability to verbalize fear and anxieties. The focus of change is directed toward cohesion, decrease in conflict, better understanding, emotional support, expression of feelings, decreased guilt, and increased communication effectiveness (Gust, 1979). Lezak (1978) suggested the importance of helping families readjust their expectations, providing practical management and advice, and most importantly, as they are the key link to the injured person, it is important to focus energy on maintaining their own well being, and alerting family members to their own needs.

Purpose of the Study

Clinical experience suggests that patients with strong family support progress further than those lacking family involvement (Mauss-Clum & Ryan, 1981). Including families in planning acute and long term care for patients can have a significant impact on the recovery process, and can facilitate the adjustment period. In particular, there is a need for information and support following discharge from the hospital when the family resumes responsibility and care for the patient.

Current studies which have examined the effects of a head injury have begun to recognize the strain put on the family (Karpman, Wolfe, & Vargo, in press; Lezak, 1978). There is an awareness that as the patient goes through a wide variety of changes, the family needs to learn to cope and adjust to the new situation. However, there is little indication of taking the step of working with the family. McKinlay, Brooks, Bond, Martinage, and Marshall (1981) interviewed families and obtained a clearer idea of the difficulties, but no attempt was made to facilitate the adjustment process. Clearly, there is a need to offer ongoing support for the families of victims.

The use of peer support groups has been suggested by F. Vargo (1984) in relation to spinal cord injured males, and by Karpman, Wolfe, and Vargo (in press) in reference to head injury. Most importantly, there is the need to study how efficacious this would be in alleviating stress during the process of adaptation to disability. Few, if any outcome studies have been completed.

Although self-help groups are emerging, they have received little systematic study resulting in few descriptive or case study accounts of a single organization (Katz, 1981), or of the effectiveness of these groups (Lieberman & Borman, 1976). There is a need to take a closer look at these groups, how they work, their patterns, the benefits resulting from involvement, and their limitations. There is a need to analyze the nature of self-help groups in practice (Richardson & Goodman, 1983).

Wright (1983) made a distinction between a disability and a handicap. A disability refers to functional limitations that result directly from an impairment at the level of a specific organ or body system. It is a medically diagnosable condition. A handicap results from the interaction of the disability with the environment and is frequently social in nature. It refers to the obstacles one encounters in the pursuit of desired goals and opportunities.

The present study examined a self-help group which can be seen as a vehicle for overcoming the handicap that results from a closed head injury. It was delimited to studying family members rather than the injured persons themselves.

McKinlay et. al. (1981), and Oddy, Humphrey, and Uttley (1978) suggested that stress levels off within six months following the injury. It is during the initial period that the family goes through a transition period and begins to compensate to its new situation. The intent of the present study was to gather information from family members once the victim's medical condition had stabilized. The main aim was to gather information on the history, organization, nature, and practices of the group and to understand the effects of the group on its members.

The author of the present study proposed to examine a self-help group consisting of families who have recently experienced a head injury in one of its members. The main purpose was to gain a clear understanding of a self-help group. More specifically, the focus was to find out about the origins, the early history, transactions, and the group's effects on family members. Following from this data, a number of post hoc hypotheses were formulated. This group already existed in the community. No active interventions were made by the researcher; rather the group was studied in its present form.

Through observation and in-depth interviewing procedures, the following research questions were addressed:

1. What was the initial intent of the group? How did the founders get the group started? What were they hoping to achieve?
2. Once the group was started, what was the nature and practices of the meetings?
3. Can a group offering advice and support facilitate the

adjustment process for family members in dealing with the issues related to head injury?

In addition to physical disability, victims of head injury suffer from severe changes in their cognitive, communicative, emotional, and behavioral abilities (Rosenbaum & Najenson, 1976). There is a consensus that the personality changes reported by relatives are certainly enough to cause distress in the family (Brooks & McKinlay, 1983; Lezak, 1978; McKinlay et. al., 1981). The importance of these changes as a source of stress strongly suggests the need for assistance as part of the routine after-care of head injured patients to facilitate a satisfying and healthy adjustment (Goethe & Lewin, 1984; Oddy, Humphrey, & Uttley, 1978). As Brooks and McKinlay (1983) concluded "one of the main thrusts of rehabilitation effort should be directed towards the family at least as much as towards the patient" (p. 343). The ultimate goal is to enable family members to function effectively while providing the most suitable care for the patient.

Significance

The intention of the present study was to provide a greater understanding of the process and functions of a support group. The study allowed the researcher to identify and determine the ways in which family members can benefit from a support group experience which may help them to continue functioning as a healthy family unit while providing encouragement for injured members to live up to their fullest potential. By examining how the group first started, and its effects on members, this study contributes to the knowledge of professionals involved with families who are coping with head injury and for those who are involved with a self-help group. It may also fill a large gap in the existing literature on the nature of self-help groups and allow one to learn more about how they affect their members.

As well, it is hoped that this study can be used as a guide. Any person or group of people who are interested in starting up a self-help group of any kind may chose to follow the lead presented by NABIIS.

Definitions

Closed head injury - nonmissile injury in which sudden acceleration or deceleration is the primary traumatic force (Goethe & Levin, 1984), a definite blow to the head resulting in altered consciousness (Jennett & Teasdale, 1981).

Self-help group - voluntary, small group structure of peers who come together for mutual assistance in satisfying a common need, overcoming a common handicap or life disrupting problem, and bringing about desired social or personal change (Katz & Bender, 1976).

Adjustment - the organism's ability to carry on those transactions with the environment which results in its maintaining, growing, and flourishing... connotes fitness, ability, confidence, and experienced success in undertakings, realistic optimism, and sustained effort in dealing with one's physical and social environments (Williams, 1979).

Effectiveness - adequate to accomplish a purpose, produce intended or expected results. For the present study, this will assume effectiveness as perceived by the individual.

Overview

A literature review on three areas which the author felt were relevant to this study are reflected in the following chapter. The characteristics and consequences of a head injury, the role and use of self-help groups, and group structure and process are discussed. The methodology used to carry out the study is outlined in chapter three. In chapter four, the results from the interviews and observations are reported. Chapter five covers the conclusions and implications which can be derived from the research.

II. Review of the Literature

A. Head Injury

Head injuries constitute a major health problem many nations throughout the world (Jennett & Teasdale, 1981) and are a significant factor in one-half of all deaths related to trauma (Friedman, 1984). The number of survivors suffering brain damage resulting from a head injury is steadily increasing due to improved intensive care treatment and advancing medical technology. Annegars, Grabow, Kurland, and Laws (1980) cited a United States National Health Interview Survey from 1975 which reported that there were 4,668 head injury cases per 100,000 population, including lacerations and contusions to the face and scalp. With these categories excluded, remaining head injury cases number 673 per 100,000. Jennett (1983) indicated that there are about seven million head injuries a year. and of these, 500,000 are admitted to hospital for care. In Canada, the incidence of serious head trauma is 20,000 to 30,000 people per year (Ivan, 1984). Incidence rates may vary slightly due to definition of head trauma, criteria used, and classification of cases.

Statistics on the cause of head injury vary slightly with the consensus that motor vehicle accidents contribute to more than half of all injuries. In a compilation of five major studies, Annegars et. al. (1980) and Cartlidge and Shaw (1981) found that up to 67% are caused by road accidents, domestic falls contribute 8-23%, industrial accidents 5-31%, sport and recreation 3-1%, and assault 2-13%. The majority of head injury victims are males at an average age of 25 with many years of active life ahead of them (Cartlidge & Shaw, 1981; Goethe & Levin, 1984; Jennett & Teasdale, 1981; Rosenthal et. al., 1983). Many will be permanently disabled in several areas of adult functioning for the rest of their lives.

In contrast to a penetrating injury, a closed head injury is caused by blunt trauma acting on the brain as a whole causing widespread and diffuse damage (Jennett & Teasdale, 1981). The severity of the damage of the injury is based on the duration of the post-traumatic amnesia (PTA). PTA is the length of time from the point of injury until continuous memory returns. PTA less than one hour is considered a mild injury, one to 24 hours is seen as a moderate injury, and greater than 24 hours is a severe injury (Jennett, 1983). In a severely injured patient, the duration of coma is an important indicator as well.

For the purpose of this study, the severity of the head injury will not be considered. Recent studies indicate that even the mildest concussion can produce central nervous system damage to some degree and results in similar lingering effects on one's life as does a severe injury (Dornan, 1985a, Goethe & Levin, 1984; Griffith, 1983).

Victim's Characteristics

A closed head injury has a large variety of consequences for the victim which take the form not only of physical disabilities, but psychological and emotional difficulties as well. The disabilities produce unique and complex adjustment problems and long term difficulties in attempting to cope with responsibilities in the areas of home and family, work or school, and social interactions (Wolfe, 1984). Substantial recovery often occurs in intellectual functions, yet overall prognosis is poor in that significant readjustment problems continue years after the injury (Miller, 1979). Secondary personality and emotional symptoms often develop, placing the patient and family under considerable stress which further interferes with the readjustment process (Cronholm 1972; Lishman, 1973; Oddy, Humphrey, & Uttley, 1978; Rosenbaum & Najenson, 1976). The impact of the injury frequently leads to chronic unemployment, disintegration of the family unit, and minimal friendships and social contact. Of the multiple consequences of head injury, there is general agreement that mental symptoms are the more persistent and constitute the major cause of disability (Dikmen & Reitan, 1977). Unfortunately, these deficits are less obvious than physical disablities, and are often not visible to others. Consesquently, they are difficult to perceive and understand (Boll, 1981; Ron, Najenson & Mendelson, 1977).

In the past, much more attention was given to restoring physical functioning than to dealing with the psychological and emotional consequences of head injury. Generally, physical deficits show a great tendency to improve and even when they do remain, they produce fewer problems for the patient and the family than do mental disturbances. According to Bond and Brooks (1976) the burden of caring for the injured patient falls on the family who are required to cope with something about which they have little information. As a result, family tensions are high and the injured patient may be rejected. In a study done by Hpay (1971), it was found that two to five years after the injury, 64% of patients had recovered from physical sequelae. However, when physical and psychological sequelae were combined, only 24% were considered to have completely recovered.

Numerous studies have explored the changes which result from a head injury. Individuals often undergo characterological changes which may result in their becoming unpredictable, disappointing, and significantly different from before the injury. Some of the personality, emotional, and behavioral changes include agitation, irritability, aggressiveness, restlessness, depression, apathy, chronic anxiety, stubborness, hostility, emotional regression, and pathological laughter (Bond, 1975; Griffith, 1983; Lishman, 1973; Mauss-Clum & Ryan, 1981; McKinlay et.al., 1981; Miller, 1979; Rinehart, 1973; Thomsen, 1974; Tobis, Pure, &

Sheridan, 1982). For adolescents, loss of ambition is a major factor (Blazyk, 1983). In addition, Romano (1974) found impairements in social judgment, memory deficits, poor attention span, and inappropriate affect. Lezak (1978) conceptualized characterological alterations into five categories: a)impaired capacity for social perceptiveness, e.g. self centeredness, b)impaired capacity for control and self-regulation, e.g. impulsivity, c)stimulus-bound behavior, e.g. social dependency, d)emotional alterations, e.g. apathy, silliness, lability, and, e)inability to profit from experience. Dornan (1985b) sugested the damage results in changes in four areas: personality, alterations in behavior and emotional stability, intellectual impairment and cognitive disability, and, disorders in mood and thinking. As a result, secondary consequences include psychosocial change, family, social, and economic disruption.

Cognitive deficits which persist long after physical recovery affect many areas including language, attention, concentration, memory, learning, and problem solving (Boll, 1981). Psychiatric sequelae such as post trauma neurosis, hysteria, and psychoses (including dementia/delirium, schizophrenia, endogenous depression, and manic states) are common (Cartlidge & Shaw, 1981). Lastly, victims have difficulty in activities in daily living (McNeny, 1983). They may be unable to practice basic skills in self-care such as feeding, dressing, and hygiene. More commonly affected are advanced living skills required for independent living such as communication skills, home living skills (e.g. meal planning and laundry), time management, and financial management.

Family Characteristics

Only recently have rehabilitation practitioners begun to move away from dealing primarily with the head injured person and toward focusing on the family unit to allow family members to learn to adjust to the characteristics associated with the injury. Changes in the injured person create an unsettled atmosphere within the family resulting in changes in many aspects of family members' lives. Family attitudes may take on a pathological form with denial of the seriousness of the injury and inability to accept the fact that further recovery is unlikely (Bond & Brooks, 1976). The family needs to learn to adjust and accommodate to the member with multiple impairments.

Dornan (1985a) believed that following a head injury the strain upon the emotions of relatives extends on a continuum through the various stages of recovery. Stage I, the acute stage causes considerable stress and anxiety concerning the prognosis. Helplessness, frustration, and grief are experienced. Stage II, the subacute stage is when it becomes apparent the patient will survive but questions arise about at what level the patient will exist. Stage III is the rehabilitation stage. Family members hoped for some degree of restoration to physical, intellectual, and emotional normality and a return of the personality that existed before the injury occurred. The family is prepared to understand the nature of any permanent disability likely to persist. Stage IV is the reintegration stage. For some, reintegration into community life may not be possible. Others may be discharged to the care of the family or to live independently.

In response to the changes, family members experience phases of denial, anger, remorse, grief, frustration, disappointment, and depression (Gust, 1979; Mauss-Clum & Ryan, 1981). One of the most devasting long term effects upon the family system is the disruption of existing roles. Family members become caretakers and are preoccupied with meeting the needs of the patient (Blazyk, 1983).

Lezak (1978) found that family members felt trapped and tied down. Often individual interests and personal needs became submerged by the needs and demands of the injured person. As well, families felt isolated and often abandoned by their extended family. In addition, it was suggested that there are special problems related to a marriage. Wives of brain injured husbands were trying to fight off frustration, disappointment, fatigue, and depression. A spouse lives in a social limbo fitting neither with couples nor singles, but becomes a single spouse. The spouse cannot mourn or grieve properly. Although a mate is lost, there has not been a death. Nor can the spouse obtain a divorce with dignity or in good conscience as feelings of responsibility and guilt contribute to a reluctance to leaving. The spouse's sexual and affectional needs can be frustrated. Many brain injured persons do not have the full capacity for interpersonal sensitivity and therefore can rarely satisfy their spouse's needs.

As a result of the losses suffered by a head injured patient, a partial death can occur. Since the recovery process is uncertain, feelings of partial death can continue for years. This grieving process has been termed mobile mourning (Rosenthal & Muir, 1983). Family members are uncertain as to what to mourn because the permanence of the losses in physical and mental functions is unclear.

In a study where relatives were interviewed and administered rating scales at three, six, and 12 months post injury, seven categories appeared as the most common changes which led to stress (McKinlay et. al., 1981). The most frequently reported changes were emotional, poor memory, and subjective symptoms such as slowness and tiredness. These were followed by changes in language, dependence, disturbed behavior, and physical disability. In response to these findings, rehabilitation has shifted to emphasize emotional and social factors in the quality of the patient's life after head trauma (Goethe & Levin, 1984).

Recent studies have reported that two thirds of relatives of head injured individuals required treatment with tranquilizers or sleeping pills. Over 50% felt they received insufficient information regarding prognosis and expectation of what was to come, and mental and personality changes resulted in more stress than physical disabilities (Panting & Merry, 1972). In a study conducted by Rosenbaum and Najenson (1976), it was found that wives of brain injured persons were more affected by their spouse's injury than wives of paraplegics. The wives of head injured husbands described them as being more dependent, childish, self-oriented and demanding. They did not share in running the household or in caring for the children. It was indicated that their disability was a social handicap resulting in a sense of isolation, loneliness, and symptoms of low mood and depression for the wives. Through in-depth interview procedures, it was found that parents become very involved and expended a substantial amount of time and energy to the recovery process. Issues of concern included financial problems, overprotectiveness, and little time for themselves (Karpman, Wolfe, & Vargo, in press).

Summary

Evidence obtained from interviews and ratings by relatives and trained observers shows that emotional and behavioral disturbances after head injury greatly affect the person's overall functioning in the family and in society. The main burdens for relatives are caused by the injured person's residual physical and emotional deficits, and by secondary alterations of interpersonal relations, family income, work patterns and social activities. Recovery from injury is a drawn out and continuous process that produces different kinds of stresses on the victim and family over a long period of time (Bond, 1983).

B. Self-help Groups

A striking recent development in the provision of social care is an enormous growth in both the number and variety of mutual aid organizations. In recent years, more and more people have come to recognize the value of getting together with other people with whom they share a common problem. Through mutual experience, they are discovering additional and alternative ways of coping with both normal and unusual crises in their lives (Katz, 1981; Richardson & Goodman, 1983; Silverman, 1980). This is especially crucial for those who do not have a natural support system (Hirsh, 1980). The self-help and mutual aid movement is a response to a number of different factors which make human services unavailable or unresponsive to those who need them. They are an alternative to extended family, close neighborhoods, alienation, and depersonalization of institutions (Gartner & Riessman, 1977). They produce substantial benefits and meet varying needs in today's society.

Definition and Typology

A number of definitions of self-help groups have been formulated, but the most widely used is that of Katz and

Bender (1976).

> Self-help groups are voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life disrupting problem, and bringing about desired social and/or personal change. The initiators and members of such groups perceive that their needs are not, or cannot be, met by or through existing social institutions. Self-help groups emphasize face to face social interactions and the assumption of personal responsibility by members. They often provide material assistance, as well as emotional support; they are frequently "cause"-oriented, and promulgate an ideology or values through which members may attain an enhanced sense of personal identity (p. 9).

Gartner and Riessman (1977) added a list of defining attributes. a)Self-help groups always involve face-to-face interactions, b)the origin of self-help groups is usually spontaneous (not set up by some outside group), c)personal participation is an extremely important ingredient, as bureaucratization is the enemy of the self-help organization, d) the members agree on and engage in some action, e)typically, the groups start from a condition of powerlessness, f)the groups fill needs for a reference group, a point of connection and identification with others, a base for activity, and a source of ego reinforcement (p. 7).

Richardson and Goodman (1983) outlined five basic functions of groups. These are emotional support, information and advice (for example, self-care) direct services such as babysitting or running errands, social activities, and pressure group activities. Jaques and Patterson (1974) suggested that a self-help group has several positive aspects for its members which cover knowledge, therapeutic and skill dimensions: a)gaining facts and knowledge of the condition; b)social learning of coping mechanisms from those who are successfully living with the condition; c)motivation and support by communicating with others who have shared a similar life experience; d)the modelling effect of successful problem-solving behaviors which provides reinforcement for new members and for long-term members; e)self-evaluation of progress resulting from feedback and sharing with members at various stages of problem, knowledge, and levels of coping behavior; f)identification with the group providing a tangible sense of belonging, of an individual and social nature, and minimizing isolation and alienation; and g)in the mutuality of the altruistic concern for others, finding self-help.

Group membership varies from comprising large sizeable organizations to small, more intimate groups. Some members seek frequent and intensive participation while others have a more limited involvement. It is common for members to join but not want to be heavily involved (Richardson, 1984).

Self-help groups facilitate a strong attachment between individuals that serve to improve adaptive competence in dealing with short term crises and life transitions as well as long term challenges and stresses. They aid in coping with stress, providing support and encouragement, promoting emotional mastery, offering guidance regarding expectable problems and methods of dealing with them, validating one's own identity, and fostering improved performance based on adequate self-evaluation (Caplan & Killilea, 1976; Katz, 1981; Pearson, 1983). In these groups, people are treated as equals where openness, informality, and friendliness are the usual way of doing things.

A basic ingredient is reciprocity. Members of self-help groups are both givers and recipients of help (Katz, 1981). The process of mutuality and the sharing of experience of others in similar situations is the fundamental concept. Knowing that others have travelled the same path leaves one feeling less isolated and more hopeful. The role of the person who has already lived through the experience is critical for helping others. It is through this interaction that members find comfort and enlightenment. Mutual asistance is established to satisfy a common need, overcome a common handicap or life disrupting problem, and bring about social and or personal change

(Romeder, 1982).

Silverman (1980) suggested that when opportunities to help enhance people's ability to cope with change are available through mutual help groups, some emotional stress may be prevented. Within the group, learning how to accept change and to make a healthy transition is facilitated. Groups are a powerful means of prevention in that they make it possible to reduce the risk of diseases that result from exposure to the stressful psychosocial situations associated with crises (Romeder, 1982) Group members have a lower incidence of mental and physical disease than their nonmember counterparts, especially under conditions of acute and chronic stress associated with rapid physical and social change (Caplan & Killilea, 1976; Romeder, 1982).

The evidence of the effectiveness of self-help groups ranges from study to study. Gartner and Riessman (1982) reported on a study of a group for widows who consistently showed better outcome on seven scales than nonmembers. The scales were depression, anxiety, somatic symptoms, use of psychotropic drugs, self-esteem, coping mastery, and well being.

Lieberman and Gourash (1979) found that elderly participants in SAGE (Senior Actualization and Growth Exploration) felt they had met their initial goals, experienced fewer psychiatric symptoms, had a marked increase in self-esteem, and were better able to cope with marital strain. The program clearly demonstrated its effectiveness in dealing with psychological distress, but had little impact on functioning in other aspects of life such as physical status or health behavior.

In a study on Mended Hearts, Videka (1979) found a general lack of evidence that this group positively effected psychosocial adaptation in its members as compared to nonmember heart surgery patients. Women who participated in a consciousness raising group showed no decrease in depression or anxiety and no increased emphasis on personal growth. The positive impact of the group was reflected in increased self-esteem and renewed self-respect. As well, no changes were indicated in coping styles and marital relationships (Lieberman, Bond, Solow, & Reibstein, 1979).

Findings on cancer self-help groups indicate that a source of help was provided for many types of difficulties encountered by persons with cancer and their families. Sharing, forming strong emotionsl bonds, and enhancing coping capacities for medical, family, social, and personal adaptation were evident (Isenberg, 1981).

Using an open-ended, exploratory approach, relying on nonparticipant observation of group meetings and interviews with group members, a survey of nine types of self-help groups was conducted. It was suggested that these groups serve a different population than do professional therapists, the groups provided social involvement, help giving processes were mainly supportive in nature, and respondants were generally enthusiastic about their group's effectiveness (Knight, Wollert, Levy, Frame, & Padgett, 1980).

Feelings of isolation and loneliness are important sources of motivation for joining a self-help group. When asked what activities members felt were most important, personal sharing was mentioned most often by 46% of the groups, educational activities by 25%, and lobbying by 15%. As may be expected, personal sharing was practiced by 89% of the groups. Educational activities were conducted by 77%; 65% practiced social and recreational activities, and 21% employed material assistance (Romeder, 1982).

Many authors have attempted to organize the various types of self-help groups into categories. Tracy and Gussow (1976) divided self-help groups into two types. Type I includes groups which focus on self-help and mutual aid, and type II groups focus on research and lobbying. Katz and Bender (1976) discussed four types of groups based on their primary purpose.

1. Groups that are primarily focused on self-fulfilment or personal growth. These groups are often referred to as therapeutic.
2. Groups that are primarily focused on social advocacy. This may include educating the public on a specific issue, changing legislation, and policies. Examples include Welfare Rights Organizations, and the Committee for the Rights of the Disabled.
3. Groups where the primary focus is to create alternative

patterns for living. This includes changing social institutions and attitudes, for example Gay Liberation, and Women's Liberation.

4. Outcast haven, or rock bottom groups. These groups provide a refuge for the desperate, attempt to secure personal protection from life pressures, and members live in a sheltered environment. An example is the X-Kalay Foundation in British Columbia.

In addition, many groups do not fit neatly into one of these four categories but are mixed and have elements from more than one. An illustrative example is Parents Without Partners.

Caplan and Killilea (1976) cited Bean who suggested three categories of self-help groups. The first type helps people with a crisis and gives information on how to cope with the problem. The need for help, support and information is initially acute, but later tends to lessen. The second type of group helps those with a permanent, fixed, stigmatized condition. The group helps deal with the condition, tries to improve self-image as well as the public image of the condition. Often, members continue attending for many years. The third kind of group helps people trapped in a habit, addiction or self-destructive way of life. The person is helped to behave differently through a variety of techniques. Attendance continues until one's life is reorganized.

Levy (1976) proposed a typology based on purpose and composition. Type I groups have some form of conduct reorganization or behavioral self control as their objective. Typical groups include Alcoholics Anonymous, Synanon, and TOPS. Type II groups include members who share a common stress and aim to relieve it through mutual support; for example, Parents Without Partners, Recovery, Inc. Type III groups are survival-oriented and provide support for a particular life style seen as deviant and subject to negative sanctions by society. Groups representing homosexuals and women's rights are examples. Type IV groups focus on personal growth, self-improvement, character development, greater joy and effectiveness in living. A good example is an integrity group which is formed by individuals who hope that collectively they can improve the quality of their lives.

Gartner and Riessman (1977) proposed dividing Tracy and Gussow's Type I groups into four categories. Groups in the first category are engaged in rehabilitative work. The physician has already dealt with patients in the acute phase, and the self-help activities are concerned with helping them adjust to their new situation. Interactions with those who have undergone similar experiences provides information on the stages of recovery, how to function and cope. Examples include Mastectomy, Inc., Stroke Club, Mended Hearts. Type II is concerned with behavior change, for example, Weight Watchers, Alcoholics Anonymous. Type

III groups engage in primary care for chronic conditions where there is no cure. Assistance is provided to patients in adjusting their life style, coping, adaptation and adjustment. Groups such as the American Diabetes Association, and the Arthritis Federation fit this category. Type IV groups are in the area of prevention and case finding. Participation to prevent illness or its reoccurence is stressed, as for heart attack victims.

Finally, the most specific typology was put forth by Romeder (1982). She divided self-help groups into eight categories. These are groups for addictions or compulsive behaviors, groups oriented toward family problems, groups for persons suffering from emotional or psychological problems, or who may have recently recovered, groups consisting of people suffering from physical handicap or chronic disease, homosexual groups, women's groups, groups oriented toward specific social action, and groups for people who have recently experienced a traumatic change in lifestyle.

It is apparent that the typology of self-help groups differs from author to author. Boundaries are imprecise and criteria used are unclear.

Professional Relations

An issue that has received great attention is the relationship between self-help groups and professional services. Are they opposing or complementary? Traditional professional models may be outmoded for modern needs. They may be seen as inefficient and ineffective, centered on control and power, based on systematic knowledge, and following a professional-dominated model. Self-help groups are centered around the consumer, are informal, open, and emphasize the subjective, the experiential and the intuitive (Gartner & Riessman, 1977). Gartner and Riessman (1977) believe these groups can humanize the professional social services.

Both self-help groups and human service agencies have similar goals - to promote and secure the well-being of their clients. A common view is that human service professionals should be prepared to recognize the valid role of these groups as an important component of the community helping network.

Borman (1979) found that in six out of 10 self-help groups, a professional played a key role in founding it, and in the remaining four, they played an instrumental role in its working. Many other studies contradict this, indicating that lay persons initiated and were key participants with slight if any evidence of professional influence (Katz, 1981; Romeder, 1980; Tracy & Gussow, 1976).

There is the belief that it is necessary to recognize the danger that professionals may interfere and impose their own ideas and methods without being familiar with the operating methods of self-help groups (Romeder, 1982). They may take over and alter the group's original purpose and play a vital role. However, professionals can contribute in many ways. They can suggest the creation of and initiate specific groups when they recognize the needs of their clients; they can offer organizational assistance and help develop them; they can refer people to groups, serve as consultants, give special advice, serve on an advisory board, help groups become independent of an agency, and act as researchers (Gartner & Riessman 1977; Hill, 1983; Silverman, 1980).

Tensions between group members and professionals go both ways. Members of self-help groups often mistrust professionals. They believe that professionals are exploitative and more concerned with economic and prestige issues, that they are not always competent due to a limited understanding of lay people, that they have limited expertise and may therefore produce unintended and undesirable side effects, particularly with people whose life situations they do not understand (Lenrow & Burch, 1981). Group members also believe that experiential approaches may be more valid than established theoretical models which are often based on studies of clinical populations that represent very limited samples (Silverman, 1980).

Professionals believe that self-help groups would be more effective if they were regulated, more efficient, and if members learned and utilized technical skills. Some see them as fanatic, or as cults. They see objectivity and the ability to remain uninvolved as essential elements in helping. Some argue that the help members provide is superficial, and does not deal with real problems (Silverman, 1980; Lenrow & Burch, 1981).

Mutual help groups and human service agencies need not be in competition with one another. They are both part of the extensive network of available community services. Self-help groups can be regarded as a supplement to professional help (Silverman, 1980). There is a need for a range of services, where one system parallels and complements the other. They can be compatible.

Limitations and Potential Dangers

While self-help groups have great potential and offer many significant advantages, there are some risks and limitations that should be considered. One set of dangers relates to the professional care giving system. Self-help groups may be offered as substitutes for the expansion of paid services, and may be used as an argument for the further curtailment of the services. They may be used to reduce professional and system responsibility, and may reduce pressure on the system for much needed structural changes. Professional agencies may attempt to dominate and socialize groups to existing professional norms. Consequently, groups can become an appendage of the professional structure, losing much of their spontaneity, innovativeness, and flexibility (Gartner & Riessman, 1977;

Romeder, 1982).

Other risks relate to the consequences for members of self-help groups. Persons involved in groups may get participation, but not help. Attention may be diverted away from resources such as possible cures and professional expertise. The anti-professional bias may prevent the useful integration of available services. Dependence may be fostered and encouraged, leading members to believe they can stay healthy only by remaining in the group. The lack of record keeping and the overall nonsystematic approach can lead to difficulties in determining accountability and effectiveness. Groups run the risk of blaming the victim if the service fails because of the emphasis on individual responsibility. They have a tendency to fragment social change as each group "does its own thing". Most self-help approaches are directed to middle class or upper working class groups. This leaves the poor underserved by both traditional agencies and self-help groups. Lastly, there is the danger that groups try to do too much or try to be all things to all people (Gartner & Riessman, 1977).

A frequent criticism of self-help groups concerns their lack of knowledge and lack of objective information (Romeder, 1982). Some groups do not make information on medical, legal, and social aspects of the problem readily available. It can be argued whether this information is important at a time of crisis.

Problems can exist within the group as well. A common one is apathy of members to get actively involved. Rather than sharing the load, few people volunteer for jobs leaving most of the work up to the more committed members, including leadership and the executive positions. Some groups have difficulty achieving a sense of common purpose among their membership. Although they join to find someone going through a similar experience, specific needs and interests vary considerably. Finally, practical problems like getting people to meetings, supporting activities and financing, and just having a place to meet need to be worked out (Richardson, 1984; Richardson & Goodman, 1983; Silverman, 1980).

Summary

Self-help groups often come into existence because services are not provided or are deficient. Persons join together to alleviate or solve some common problem. They encourage participation and foster mutual aid on the basis of a common experience and understanding. Groups combine a number of very important properties. These include the helper-therapy principle, the use of peer support, the aprofessional dimension, the demand that one can do something for oneself, and consumer intensivity. Groups show that people need not be passive, that they have power. They may permit dependence yet foster autonomy and independence; they can give support while demanding action and work. They enable members to feel and use their own strengths, and power, and to gain control over their own lives (Gartner & Riessman, 1977). They contribute in terms of prevention, restoration, maintenance, and improvement of health, mental health in particular. Self-help groups are inexpensive, highly responsive and accessible to the consumer.

C. Group Structure and Process

A group involves two or more people in a functional relationship and in interaction with one another with the aim of achieving a common goal. A group's purpose may include the completion of specific goals, the maintenance of a group or national identity or the pursuit of mutual enjoyment and satisfaction. Groups have the potential for an impact on their members through shared psychological states. They are typically held together by a common objective.

There are two types of groups - primary and secondary (Calhoun 1976; Lindgren 1973; Hollander, 1981). Primary groups originate spontaneously rather than by deliberate effort or plan. Members know and interact with one another face to face, contacts are likely to persist over a long period, people are likely to respond to each other as whole personalities, and the intensity of the relations are likely to be great. Members show loyalty and solidarity, and provide a high degree of social support and strength for one another.

Secondary groups are deliberately formed, contact among members is not typically face to face to the extent found in primary groups, contacts are likely to be of shorter duration, intensity is less strong, and the group involves a single aspect of the lives of its members. Being identified with a secondary group is not a goal in itself but is a means by which other goals may be achieved. Interactions are more formal and impersonal than in primary groups.

Groups may be formal or informal. In formal groups, structure is imposed from the outside. They are specified by regulations, as is found in organizations. Structure in informal groups comes from within (Hollander, 1981). Goldstein (1980) proposed that distinctions on different types of groups are based on size, intimacy, function, and membership. With reference to size, groups can be large or small. The smallest group is a dyad. Groups over 30 members are considered large. In large groups, personal interaction with each of the other members becomes difficult, subgroups often form, and formal structure and division of labor is likely. Intimacy is dependent on whether the group is primary or secondary. Members of primary groups have close contact, and the group is fundamental to the development of values, attitudes, aspirations, and feelings. Relations among secondary group members are less intimate and personal. Groups take on one of two functions. Task oriented groups form for the limited and specific purpose of attaining a goal. Socio-emotional groups exist to satisfy the social and emotional needs of their members. The interaction itself is the major purpose of the group. Groups are not necessarily one or the other but fall somewhere on a continuum. Membership requirements are ascribed or achieved. Some groups are ascribed or automatically joined by virtue of personal traits such as gender, ethnicity, or religion. There is a low degree of choice in ascribed groups. Others are achieved or joined voluntarily and there is a high degree of choice, such as a political organization or a professional association.

Individuals are attracted to groups for a variety of reasons. Groups can serve social and emotional needs. They can provide prestige, a sense of self definition and feelings of belongingness. They can serve an instrumental function of enabling the individual to achieve goals as a member of the group that cannot be achieved alone (Shaver, 1981). If a group is to function, it must motivate people to participate. It strives to engage their loyalty and stimulate morale and enthusiasm. Members tend to share common beliefs, attitudes, values, and perceptions (Calhoun, 1976). They involve interaction, effective ties and interdependence of roles.

Group Performance

An essential characteristic of a group is its performance as an integrated unit. It performs some function as a system, such as attaining an objective and common goal. Generally, it is believed that collective performance is superior to individual performance. Social facilitation theory refers to the improvement of individual performance in the presence of other people (Freedman, Sears, & Carlsmith, 1981; Wrightsman & Deaux, 1981). Being in the presence of another individual increases one's drive, motivation, and is a source of general arousal. As well, it raises concerns about being evaluated by others. However, this may facilitate performance or interfere with it. With responses that are well learned, and with simple tasks, the result is an increase in performance level. In contrast, responses that are not well learned or are complex will suffer from this drive. In a study by Bray, Kerr, and Atkin (1978), it was found that groups solve more problems than individuals, and the larger the group, the greater the advantage over one person working alone. However, groups were less efficient than individuals because they solved fewer problems than the same number of separate individuals working by themselves, especially on difficult tasks.

A number of factors can influence group performance (Shaw, 1981). Effectiveness depends on the task, cohesiveness, communication patterns, size, group composition, and identification with the goals (Newcomb, Turner, & Converse, 1965). Performance is determined by clarity of goals, freedom from ambiguity and conflict, and a strong commitment by members to the purpose of the collective group (Freedman, Sears & Carlsmith, 1981).

When a group is making a judgement or learning material in which accuracy is most important, the larger the group, the more accurate the judgement will be. When a group is engaged in a task in which speed is important, small groups are more effective than larger groups, particularly if performance requires consensus. Consensus is often difficult to achieve in larger groups and problem solving time is devoted to resolving initial differences of opinions. When each group member has something unique to contribute to the solution, groups will be more effective than individuals. In brainstorming, larger groups generate more ideas (Stang, 1981).

According to Goldstein (1980), task performance depends on three variables.

1. Task demands consist of the requirements of the task and the rules under which the task must be performed. Unitary tasks cannot be easily broken down into smaller subtasks. Divisible tasks allow for specific subtasks to be assigned to some group members.
2. Resources include all the relevant knowledge, skills, and abilities possessed by the individual members of the group.
3. Pressures toward conformity and uniformity during the acutal performance of the task make up group processes.

The presence of others can lead to competition or cooperation. Competition is concerned with personal goals where individuals try to secure a greater than equal share of the rewards. Cooperation involves mutual goals (Lindgren, 1973). Competition increases tension, promotes hostility, and may create prejudice. Cooperation reduces tension, creates good will, promotes friendliness, and is a powerful force that can lead to more communication, trust, attraction, satisfaction, and helpfulness (Berkowitz, 1980; Stang,1981). Competitive goals discourage the organization of purpose and unity, can breed conflict among members and are counter to organizational goals. Cooperative goals foster organization (McDavid & Harari, 1974).

To increase problem solving effectiveness, group members should be willing to tolerate a difference of opinion, bring in outside experts, and assign one member to play the role of devil's advocate and challenge proposed solutions. If members are encouraged to be critical, "groupthink" can be prevented (Wrightsman & Deaux, 1981). Trained leaders improve task performance by restraining the aggressive and domineering members and allowing others to be heard. Group functioning can be facilitated when positions and roles are well defined, and some sense of structure is maintained (Lindgren, 1973). The ability to communicate also plays an important role in determining group performance (Freedman, Sears, & Carlsmith, 1981).

Cohesiveness

Cohesiveness is a member's commitment and attraction to a group (Freedman, Sears, & Carlsmith, 1981; Lindgren, 1973), the degree to which they unite and stick together, and their overall motivation to belong (Berkowitz, 1980). Members of groups that are high in cohesivensss find a high degree of satisfaction and little incentive is required to convene them. Groups low on this factor must be maintained by some external pressure. Cohesiveness is facilitated by a perceived similarity among persons, and groups are less cohesive when members belong to other groups as well, when formed spontaneously, and when they are convened by an external authority. A high degree of cohesiveness in a group enables and encourages members to identify themselves with the group and to become involved in its tasks to the point that the group's success or failure becomes their own (Lindgren, 1973).

A group with high cohesiveness has a strong motivation and strong pressures against conflicts that could interfere with performance. The greater the cohesiveness, the cleaner the definition of the boundaries and the sharper the distinction between members of the group and nonmember outsiders, thus leading to greater resistance to threat of disorganization (McDavid & Harari, 1974). Members are more apt to be compatible, conform to norms more, have better morale, and follow the group's goals.

Sharing is a necessary precondition for cohesiveness. Members need to know each other's attitudes, and need to feel thay are not alone. Structural integration facilitates efficiency and coordinated performance that is rewarding to group members. Therefore their attraction to the group is reinforced and increased (Newcomb, Turner, & Converse, 1965).

Initiation in groups may influence cohesiveness. Persons who had difficulty achieving entry (McDavid & Harari, 1974) or endured a painful initiation may be more likely to attach high value to belonging to it. The extent to which the group meets the interpersonal needs of those who belong, and the extent to which the group accomplishes the goals for which it was formed can determine cohesiveness. Groups in which members are considered pleasant and similar in values, interests, and beliefs are highly cohesive. A group's attractiveness may be influenced by the nature of its leadership. Studies indicate that people prefer a democratic, participatory form of leadership rather than an authoritarian, dictatorial leadership (Middlebrook, 1974).

Members of highly cohesive groups are more satisfied with their groups, have a lower rate of absence, a greater amount of participation, assume responsibility, participate more fully at meetings and remain members longer. There are personal consequences as well. The level of cohesiveness is correlated with fulfilling the member's need for security, increasing sense of personal worth and decreasing anxiety level. Cohesive groups exert strong influences on their members. Members of highly cohesive groups are more pleased about their membership, communicate more often and in a more cooperative manner with one another, and have much more social influence on each other than members of groups low in cohesiveness.

According to Hollander (1981), there are three recurring factors regarding member satisfaction. These are status consensus (indicating the degree of agreement concerning group structure, particularly leadership), member's perceptions of progress toward group goals, and perceived freedom of participation within the group. These three factors provide the individual with a sense that there is a stable environment within which to make contributions that are rewarded.

Cohesive groups are better coordinated and have a greater feeling of solidarity than noncohesive groups. Cohesiveness implies a concern for others and a readiness to do what is expected of them. It is associated with conformity and communication, and effected by motivation of the group to succeed on a task, its prestige, and its efficiency in working toward its goals (Stang, 1981).

Leadership

Groups almost always have a leader particularly when the group is large, the task complex or important, and decisions must be reached quickly. Middlebrook (1974) suggested that the emergence of leadership is vital to the effective functioning of a group. A leader is someone who exerts more influence than other members of the group. A leader initiates action, gives orders, makes decisions and judgements, has power, and initiates structure and direction to the course of the group's activities (McDavid & Harari, 1974; Freedman Sears, & Carlsmith, 1981). As well, this individual offers encouragement, inspiration and is the forefront of activity.

Effective leaders are likely to show consideration and be particularly sensitive to the feelings, attitudes and needs of other group members. They are flexible in adapting their abilities to changing demands, are responsible in exerting initiative toward the group's success, and are successful in facilitating the attainment of group goals (Freedman, Sears, & Carlsmith, 1981; Goldstein, 1980). Leaders are chosen based on social desirability, such as friendliness. They are the most active communicators, speak freely and easily, and consequently determine the course of the conversation. Extraversion, self-confidence, charisma, high activity level, intelligence, and assertiveness tend to characterize them (Freedman, Sears, & Carlsmith, 1981; Shaver, 1981). The leader tends to be someone with similar values and opinions as the group. This person is someone not too different from the rest of the group - one of them, but the best of them.

Some leaders are appointed, others earn their position. Appointed leaders need to legitimize their position by demonstrating their ability so that they will be effective. Elected leaders need to perform well [illegible] maintain members' support. A democratic leader allows the group as a whole to make decisions, allows members to choose the jobs they want to do, issues few orders, and serves primarily as a guide or chairperson. In contrast, authoritarian leaders make most of the decisions on their own, issue many orders, and are generally commanders of their group.

Freedman, Sears, and Carlsmith (1981) believed that often, two kinds of leaders emerge within a group. A socio-emotional leader handles social aspects of the group, keeping it running smoothly and happily, and a task leader focuses on the job and getting the work done. Shaver (1981), and Stang (1981) suggested that these two specialties emerge among group members as well. A socio-emotional specialist shows solidarity, provides tension release, agreement, improves morale, tends to be positive, and keeps relations warm and friendly. This person tends to be the best liked group member. A task specialist is efficient and competent in a particular task in which the group is engaged, and will therefore generate ideas and provide guidance. This individual asks for and gives information, opinions, suggestions, contributes substantially, and is perceived as having the best ideas.

Summary

Interaction between members, the development of shared perceptions, the presence of emotional ties, and the development of interdependence are all properties found in a group (Wrightsman & Deaux, 1981). In our society, individuals are affiliated with many groups. Group performance is affected by a variety of factors including its structure, communication patterns, cohesiveness, leadership, and the process in the specific task it hopes to achieve. The more cohesive the group, the more members have an inherent interest in the consequences of their collective performance and outcome.

III. Methodology

A. Theoretical Underpinnings

Little is known about the process which occurs in a self-help group. "The development of measures and methods to assess the impact of these groups on the lives of their participants is required" (Lieberman & Borman, 1976, p. 458). Measuring the impact of groups on their members using standardized techniques would be very difficult. Investigations of self-help groups must include other methods in the pursuit of holistic knowledge. Qualitative research is exploratory in nature, and may be described as humanistic, descriptive, experiential, phenomenological, observational, case study, field work, participant observation, and process evaluation. Process evaluation is a qualitative consideration of the specific events in a program including the typical experiences of participants (Campbell, 1978). This perspective allows for the participant's reality to surface. The focus is on the self-help group's process and structure taken from the vantage point of its organizers and its members.

The intent of the participant observer is "to catch the process as it occurs in the experience of those he studies" (Bruyn, 1966, p. 13). Bruyn put forth three axioms which reflect the field researchers' experience. Firstly, the participant observers share in the life activities and sentiments of people in face-to-face relationships. Rather than remaining unmoved, unchanged, and untouched as is the traditional role of the scientist, participant observers share the sentiments of people. Consequently they are changed and may change the situation to a small degree. Therefore, the role of participant observers requires both detachment and personal involvement. Secondly, participant observers are a normal part of the cultures and the lives of the people under study. The amount of disturbance caused by the researchers' presence is minimized in order to interpret more adequately the natural functions governing the life of the group. The scientific role of participant observers is interdependent with their social roles in the culture of the observed. Researchers are interested in the people as they are, not as they should be according to the observers' own standards. Thirdly, the role of participant observers reflects the social process of living in society. The social process being examined will have meaning for people in groups outside of those being studied.

This study reflects the participant observer and process evaluation frameworks. The researcher attended a number of events and meetings over an eight month period as a participant observer. Consideration has been given to specific events as well as to typical experiences of the participants involved.

Cronbach (1982) suggested that no outsider can specify in advance what is important to observe. Only the person affected by the program knows what is personally important, and can interpret its outcomes. Therefore, what is important, then, cannot be manipulated, standardized, objectified, or quantified. Open minded exploration with attention to qualitative information is more flexible and broader in its coverage.

Unstructured opportunities to exchange ideas and feelings freely in interviews and direct observation permit the researcher to understand the world through those who are experiencing it. The methodological techniques used must be flexible and unobtrusive. Direct contact would be the best way to achieve a better understanding of the personal experiences of group members. Open communication fostered in unstructured or semistructured interviews and observations serves this purpose (Isenberg,1981).

In the present study, the author intended to gain a clear understanding of the nature and practices of a self-help group. Consequently, it was exploratory in nature. This idea is reflected in grounded theory (Glaser & Strauss, 1967). Grounded theory is the discovery of theory from data systematically obtained from social research. One of the purposes of qualitative research is the generation of hypotheses rather than the testing of hypotheses. The intent is to explain a phenomenon as it currently exists by closely examining the data. Grounded theory is derived from data and then illustrated by characteristic examples of data.

B. Sample

The self-help group which was studied is the Northern Alberta Brain Injury Interest Society (NABIIS) in Edmonton. In a newsletter (September, 1983), NABIIS was described as follows:

> NABIIS has been formed to serve and promote the optimal lifestyle of persons who have suffered brain injury and that of their families. A registry will be established to compile information for and about head injured persons. Local support groups will be formed to provide support to families and head injured persons closer to their home areas. Also the group will be involved in promoting public awareness and research where possible.

NABIIS is open to victims of head injury and family members. It was incorporated in July, 1983. Meetings occur on a monthly basis in the form of a coffee house and are open to anyone in the community who may have an interest in learning more about issues related to head trauma. Presently, there are over 100 paid members. Usually 20-30 people attend the coffee houses, some regularly, others periodically. As well, there is an annual meeting, four general meetings held every three months, and monthly board meetings held for the executive members.

As the study was getting underway, all family members who attended board meetings and coffee houses were approached and asked to participate. Ten family members were available and willing to be interviewed regarding the perceived effectiveness and outcome of the group. As well, through talking with people involved with NABIIS, it was discovered that there were six people on the initial steering committee. Interviews with five founding members of NABIIS were conducted to obtain information on the initial intention and objectives of the group. One member who was involved in the early planning of the group was unable to be contacted.

Demographic data indicate that the 10 family members who participated in this study represent a varied group. (See Table 1) There were two fathers, two mothers, four wives, and two daughters. The mean age of respondants was 43 years with a range of 22 to 65 years. Nine out of 10 were married and had one to four children. One participant was single. At the time of the interview, only three were employed outside the home - two full time, and one on a part time basis. Before the injury, six were working and two were teenagers. Four of the six said they stopped working as a direct result of the injury. Two people were retired. Participants were basically working class persons with a high school or college education. One had a university degree.

When questioned about the use of any outside services, the common response was that there were no home services. Two people used assessment services, two used a van or transportation system that could accommodate a disabled person, one used a local extendicare hospital, and one a residential hospital.

Injured persons were comprised of three sons, one daughter, two fathers, and four husbands. Their mean age was 35 and ranged from 27 to 49 years. No one was employed except for one who was working in a sheltered workshop. One person was pursuing academic upgrading. All but one of the injured persons received some form of disability pension or insurance settlement. Two were still waiting and hoping for an insurance settlement. The injury had occurred seven months to eight and a half years prior to this study.

Table 1: Demographic Data

Family Member	Age	Injured Member	Age	Date of Accident
father	62	son	27	Feb, 1982
mother	52	son	27	Feb, 1982
wife	32	husband	27	Nov, 1982
wife	26	husband	27	Nov, 1984
daughter	22	father	40	Feb, 1977
daughter	22	father	44	Jan, 1982
wife	48	husband	44	Jan, 1982
wife	43	husband	49	Feb, 1977
mother	64	daughter	35	Jan, 1981
father	65	son	28	Aug, 1980

C. Procedures

A significant amount of information was gained by attending meetings as a participant observer paying special attention to the process and interaction of members. More specifically, the researcher looked for any reoccuring structure, at the group's primary focus, issues and concerns that arose, leadership, and the role of the professional. In this role, the investigator attempted to blend in and be viewed as just one of the group. As well, individual interviews were conducted with founding members of NABIIS regarding how and why the group began and with family members to explore the effects the group had on them. Interviews were semistructured in that some questions were prepared prior to the interview. However, participants were encouraged to share any information they felt may add to the researcher's understanding of the group and their experiences.

Prior to the start of the interview, the participants received an explanation of the purpose of the study and were asked to sign a consent form (see Appendix A). An outline of the interview format can be found in Appendix B. Interviews varied in length from 30 minutes to two hours. All individual interviews were tape recorded. Where appropriate, group sessions were tape recorded. Alternatively, extensive notes were kept. As well, any documents related to the group and minutes of meetings were available.

The investigator attended six coffee house meetings, four board meetings, and one session each of the annual and general meetings. As well, the author participated in brain injury awareness week. It was anticipated that this would cover a broad range of NABIIS activities and allowed for a good understanding of the nature of the group.

To obtain a measure of reliability, transcripts of sessions were returned to group members and three of the initial interviewees to insure that the essence of their experience was being captured. Participants were asked to read through them and report back as to whether or not they were an accurate description of their experience.

The role of the researcher can have an influence on the results of this study. In defining the relationship with those persons who were studied, two things were kept in mind. First, there must be an ethical relationship in which the first concern was to respond to the needs and interests of those being studied. The second concerns maintaining the objective goals of the study by remaining nonjudgemental, and not becoming so involved as to lose the scientific aim of the study (Isenberg, 1981). Throughout the study, every attempt was made to heighten objectivity as much as possible.

The author would like to comment on two personal biases. One belief is that groups can be effective in helping an individual work through and adjust to a personal problem. Members can alleviate some questions and concerns by sharing common experiences. Another bias is that family involvement can have a positive effect on rehabilitation for an injured member. Support and encouragement from significant others is important in the recovery process.

Sampling bias is virtually inherent in the study of self-help groups. Membership is voluntary and made up of persons who are self-defined sufferers of the problem which constitutes the focus of each group (Knight et. al., 1980). This study was primarily concerned with a small number of individuals who have voluntarily agreed to participate in a study of a self-help group to facilitate adjustment to living with a closed head injured person. Consequently, although it is hoped that the results may apply to other self-help groups, the ability to generalize to all persons in similar situations is limited.

D. Data Analysis

As this study is exploratory in nature, no specific hypotheses were being tested. Rather, the information obtained from participants are presented in a descriptive manner.

Stake's (1967) model of group evaluation was chosen as the conceptual framework and adapted for this study. Data are presented in accordance with this design. The data are examined and described under the headings of intent and observations. The intent covers the objectives for starting the group, the anticipated process which was to occur in sessions, the goals that were planned for, hoped for, and anticipated. This was obtained through interviews with founders of NABIIS. The subsequent consequences, what is now actually taking place will be considered the observations. This information was obtained through group observation and via interviews with group members.

In addition, intent and observations were further divided into three conditions-antecedents, transactions, and outcomes. Antecedents are conditions existing prior to the experience which may relate to the final results. Events existing before the formation of the group (intent) and prior to members joining (observations) will be discussed in this condition. The second condition, transactions, are the succession of encounters, interactions, and the dynamics which comprise the process of the group. These were obtained by interviews with founders (intent) and by attending and observing group sessions (observations). The third condition, outcomes, are the result of the experience which measures the impact of the group, and were obtained through individual interviews with both founders (intent) and group members (observations). Stake (1967) suggested that these characteristics are often observed in a direct and personal way.

Intent –Antecedents
–Transactions
–Outcomes

Observations
–Antecedents
–Transactions
–Outcomes

E. Interview Schedule

The interview schedule was based on a review of the literature of self-help groups. More specifically the interview schedule for family members was based on the questionnaire used by Knight et. al. (1980). Questions for both groups were then divided under the headings proposed by Stake (1967). In addition, any issues raised in initial interviews that had not been included in the schedule were later added in order to make the questions as comprehensive as possible. (See Appendix B).

IV. Results and Discussion

The following is a compilation of the interviews conducted with the five founding members of NABIIS who subsequently formed the first steering committee. The interviews are reported and reproduced as close to verbatim as possible to insure accuracy. (See Appendix D). The interviews are presented in accordance with the headings previously outlined in Stake's (1967) model.

A. Intent

Antecedents

NABIIS grew out of a family education group which was run at a local hospital as part of the brain injury rehabilitation program. Family members were attending a brain injury family education series which was held sequentially one evening a week. The series consisted of presentations and discussions on five topics. The topics were: 1) the brain and brain injury, a general overview, 2) physical and ADL (activities in daily living) rehabilitation, 3) communication and cognition, 4) patient care and fostering independence, and seizure management, and 5) family adjustment to trauma. These sessions were given by hospital staff and geared mainly to adult family members and friends.

Soon after the series began, there was a request from participants as well as other nonattending family members that they should get together on a regular basis, particularly because there were no support services outside of the hospital for brain injured individuals. Upon leaving the rehabilitation hospital the only options were to go home or go to an institution. There was no follow-up. Families had to deal with the situation by themselves. The co-ordinator of the education series, a psychologist, thought that he might get a whole group of people together who would have enough energy left after the trauma they had recently endured to start up some kind of group.

Concurrently, a group of people were meeting at a second local hospital every two months. They would occassionally bring in a guest speaker to talk about issues related to brain injury. The co-ordinator of the first group proposed combining the two into one formal, larger group. To find out how much interest there was, the first organizational meeting took place in November, 1982. Through the use of medical records, people who were living with a brain injured person were contacted and told of the meeting. As well, notices were posted in the hospital. Approximately 40-50 people attended from all over Northern Alberta. The outcome of the meeting was a group consensus that a Northern Alberta organization should be established to support the efforts to assist in the rehabilitation of individuals with brain injury. A couple of months later (January, 1983), a second meeting was called for specific planning and to discuss and outline what the group wanted to do and the position they would take. Through a request for volunteers, a smaller steering committee was established to organize these matters. This committee subsequently became the first board of directors. The steering committee met every few weeks to discuss objectives and the basis with which to start and develop the organization. The groundwork was done to establish a constitution, compile by-laws and objectives for submission to the Societies Act, and apply to the government for a society's number. The committee then decided to create a newsletter and a logo for their letterhead. At that time it was decided to call this new group Brain Injury Interest Group (BIIG). This was later changed to Northern Alberta Brain Injury Interest Society (NABIIS) because it had to incorporate the region, and the word society. At this early stage, NABIIS wanted to let people know that the group existed. They set up a liason with community hospitals, sent out brochures to community facilities and local hospitals, invited people to the education series, and had a group of visitors who were willing and able to go to families while they were still in the acute hospital and invite them to use NABIIS as a resource. NABIIS was not yet providing any services.

There were many initial reasons for getting NABIIS started. Firstly, and primarily, it was for family and victim support. People felt isolated from each other. There was little support in the acute stage, little support in the rehabilitation stage, and none at all once the patient was discharged from the hospital. The family was left to fend for themselves. There was a strong need to meet others whom they could talk with who finally truly understood what they were experiencing. The group was to provide mutual support and encouragement. It was to be a place to talk about problems, as well as share successes. In addition, it was hoped that groups in smaller outlying communities would develop to provide mutual support nearby without having to travel to a main centre many miles away.

Secondly, community facilities for people with brain injury did not exist. People expressed great concern that there were no services, nowhere to turn. Although there were facilities for many other disability groups, it was felt that people with a brain injury had very specific needs that could not be met in other situations. They did not easily fit in with the mentally ill, mentally retarded, or the physically disabled. It was thus necessary to establish specific centres for brain injured persons. This was to include long and short term housing arrangements such as a therapeutic group home where they could go for a day or longer and be supervised, as well as an out of hospital educational and vocational training centre.

Thirdly, there was a need for public relations. One of the many functions of the group was to promote public awareness about brain injury, its consequences and effects. It was important to lobby for the needs of the brain injured and advocate for appropriate services.

Fourthly, there was a need to provide a library and resource centre for basic information. Few families had any idea of what they would be facing once the injured person was out of intensive care. They received little information of what to expect and much of this was in medical terms making it difficult for them to fully comprehend and get a realistic expectation of the future. As well, in the initial stage after the injury, being in a stage of denial, many were unable to believe what they were told of the wide range of sequelae that were to follow. NABIIS was to provide the service of going to the hospital to talk with newly injured persons and their families. This would be an opportunity to make them aware of what exists in the community, what is available for their use, and to tell them that there was an education series, and a library available for their use. The resource library would result from researching what was available in terms of rehabilitation, relief, recreation, education, all available programs and facilities. This information was to be put into a reference file for public use.

Fifthly, NABIIS hoped to be able to provide a registry of names available for other head injured individuals and their families. This was especially important for those who lived in smaller outlying communities. This would also provide some statistics on the incidence and type of injury.

Transactions

Initially there were to be both professionals and family members actively involved in the group. Professionals saw the lack of facilities in the community and recognized the need for the group, and were more than willing to help it get off the ground. There was a psychologist, a nurse, and a physiotherapist. The nurse provided the contact with the other hospitals and acted as the hospital liason representative. In the early phase, the professionals were the backbone of getting NABIIS started. As the group progressed, professionals were to slowly pull away into the background as family members were to pick up and move forward on their own. Key board positions were to be held by family members as the focus of the group was to deal with and respond to family concerns. The role of the professionals was to be supportive, back up the group in its endeavors, and to offer and provide any required information in their areas of expertise. They were to keep the group on the track. As well, they had more access to people in the acute care hospitals.

The group was to initially meet in a local hospital which agreed to provide them with a meeting place and some essential services such as duplicating and audio visual equipment. It was anticipated that the group would soon raise some funds to allow themselves to set up elsewhere in the community. They wanted to move into their own space outside the hospital to allow themselves to gain and establish their own identity. Funds were to be obtained from donations, membership fees, and eventually, BINGOs. (See Appendix C for a chronological development of NABIIS).

Initially, members were recruited through hospital records. Those who responded to letters were then put on the NABIIS registry. Families of brain injured persons were contacted and told about the beginning of NABIIS. Participants in the education series were invited to join, newsletters were sent to families who they thought may be interested, and brochures were sent out to hospitals. Occassionally other community hospitals would refer people to the group, physicians who worked with brain injured were sent brochures to be passed on to their patients, and most of all, the news of the group was spread through word of mouth.

In April, 1983, it was decided that meetings would take the following form. There would be a monthly board meeting to discuss business, quarterly general meetings, and an annual meeting. These were open to anyone who had an interest. Later, as there was a strong demand for a time when they could help each other rather than talk business, support groups for injured persons and family members were to begin and meet once a month as well to give people a chance to meet informally. These were to be in the form of an informal coffee house. Discussion and socialization were to occur. There were to be various guest speakers, fund raising activities, and possibly some social events that would become yearly activities. As well, it was hoped that some committees would be formed to get more people involved and help spread the work around.

Outcomes

The central theme of NABIIS was to provide emotional support and to be a family support service. The primary goal, or the effect the group was to have on its members was to provide a sense of community and a sense of identity. It was to give the realization that members were not alone to face their kinds of problems. It was to provide the opportunity for people dealing with a similar situation to get together to talk about it. As well, the group was to provide a place to share frustrations, encouragement and support. It is important for members to know they are not alone and are not helpless. As one person who was interviewed said "It's very lonely. When you are lonely, you get discouraged, and when you get discouraged you give up. The idea was to reverse this process." Other short term goals included providing a registry, resource centre, and public awareness through advertising, brochures, and posters.

As well, there were many secondary, or long term goals. NABIIS hoped to branch off and provide local support in smaller communities. The group hoped to establish immediate and ongoing counseling for its members to be provided by a mental health professional who was familiar with the prevalent issues. They wanted to establish a relief service to relieve family members for caring for the injured member on a constant basis, as well as a type of housing or day care centre where injured persons could be supervised for a full day. This facility would incorporate a program to help persons improve their skills in their areas of weakness, and some workshops that may eventually lead to job placement. This facility was to be community run rather than hospital based. Also, NABIIS hoped to get some research going and to gather statistics, especially in Canada.

B. Observations

Interviews with the 10 family members, and observed group sessions, have been compiled and can be reported as follows. Again, every attempt was made to maintain accuracy by using the words of the participants. (See Appendix E).

Antecedents

Family members learned about NABIIS in a variety of manners. Commonly, for seven family members, the first mention of NABIIS was made at the rehabilitation hospital. Through meeting with staff personnel who worked with the head injured, they were told about the group. One person was told about the group by the social worker while still at the acute care hospital. One person saw an article in the local newspaper about a family who was adjusting to a head injured member, called them, and was told about NABIIS just starting to get underway. One individual wanted to get a group started, called the hospital and found out that NABIIS had just had its first meeting.

Three members joined NABIIS at the very beginning and two of these became involved in founding the group (November, 1982). Two joined in early 1983, two joined in Spring, 1983, one in November, 1983, one in early 1984, and one in February 1985. All 10 said they anticipated their membership to be permanent, as head injury is forever.

The common thread of why people joined NABIIS was because they found others who could finally understand what they themselves were going through. It was a place they could talk with others and share common experiences. Particularly when a spouse was injured and the support and sharing was lost, often leaving one feeling very separated, meeting with other spouses helped one through. Those who were struggling to cope with a recent injury felt they needed to hear what others had gone through. Just listening to them made them feel less alone, that they were not the only one feeling as they did. Especially when family and friends do not stay around, it is good to have others to talk to.

Some were looking to learn of ways and means to find programs to work with injured members, and were looking for any ideas and information that they could use. It was a searching out to hear what others had tried, what worked and what did not. It also gave a sense of fellowship.

For two individuals, the memories of what they had gone through a few years earlier were strong. They had managed to get through an extremely difficult experience and felt there must be some reason for the accident, something positive had to come out of it. Consequently, they got involved in NABIIS and are trying to promote the group and establish much needed facilities. One mentioned that if the group was going to help others, she would put her best into it. Three people who felt the need for this type of organization hoped that the more backing the group got, the better chance it had to develop and they wanted to help support it.

Transactions

Those interviewed attended as many meetings as they could. For three families, there was the difficulty of getting a babysitter which often kept them from attending some meetings. The most widely attended meetings were the annual and general meetings, and nine out of 10 people interviewed attended many or all of the coffee houses. Those on the executive regularly attended the board meetings. Each individual's contribution varied. Again, most attended whatever meetings were possible. Five were board members and regularly attended monthly meetings. Six volunteered to do occasional BINGOs, two attended BINGOs regularly and consistently. One made a significant contribution by designing and putting the newsletters together which are issued quarterly. All volunteered for community events whenever their time was needed. Some volunteered for everything. For example, for the first public awareness week many hours were spent on their dove day drive (passing out doves mounted on orchids for donations), sitting at a booth in a local mall, organizing public service announcements on radio, television, and newspapers, and sending out letters to sources in the community.

At the monthly coffee houses, attendance usually ranged from 20 to 30 people, one had eight people. For five out of six meetings everyone present met together. For one, when there were over 30 people, the group split into two - those who sustained the brain injury, and family members. There have typically been mostly injured males, two or three injured females, two to five family members, and one or two people who work with the brain injured and were interested in learning more about them (i.e. representative from Worker's Compensation Board). At one coffee house there was a slide presentation on a recreational program followed by informal discussion and socializing. Coffee and snacks are always served.

Meetings were friendly and informal. The format generally consisted of all participants taking a turn to introduce themselves and talk about th accident, the course of the injury, what they were presently doing, and how they were feeling about themselves. This was particularly geared toward new people. People were willing to share and relate personal experiences. The sincerity and understanding with which people listened to each other was apparent.

Although many participated in the discussion, a definite leader emerged. The leader was very sensitive and warm and had a good sense of humour, often sharing jokes and telling stories. He was very willing to share his own experiences, provide information when appropriate, and contributed to the group running smoothly. Often, members would share information on various community facilities and programs and upcoming events. They talked about personal difficulties, for example, body changes, loneliness, thoughts of suicide, and fatigue. Topics of discussion varied including rights of injured persons, insurance policies, lasting consequences of brain injury, the needs of the brain injured, and sports.

There was one coffee house that only eight people attended and it was led by a professional. It was somewhat different in that every one participated. There were two head injured individuals who, before, had not contributed to the discussion. This evening. however, they both spoke regularly, shared their feelings and their own experiences about the consequences of their injury. This may be attributed to the smallness of the group and the structure added by the professional leader.

When the coffee house split into two separate groups, I joined the group with family members. No leader emerged. Everyone spoke and contributed to the discussion. The meeting began by focusing on a member whose husband was recently injured. The group provided information on available community resoures and offered support and encouragement. They appeared pleased to be able to help someone else especially since the information they were offering her was not available when they were facing their own family member's injury. Discussion then moved to events that were coming up, fund raising activities, and what they hope to accomplish in the near future.

Coffee houses were friendly social gatherings. No pressure was put on anyone. Each individual could choose to contribute. Some sat quietly and listened. Occassionally people would split into smaller groups so more than one conversation could be going on at any one time. Sessions tended to last for two hours.

Six to ten members generally showed up for board meetings. This included the president, vice president, secretary, treasurer, a hospital liason representative, and one or two information committee representatives. Occassionally, someone who had an interest in NABIIS or brain injury would attend as well. Various business issues were discussed including the treasurer's report on available funds and their allocation, planned events, activity reports, community response to the group, and an update from all board members. It was always led by the president but anyone was free to add input and information, and make suggestions.

The general and annual meetings tended to be larger than the monthly meetings. Forty to fifty people typically attended. One general meeting, to kick off brain injury awareness week, had about 100 people, many of whom were new to NABIIS, had not been to previous meetings, and had not been involved before. The format included one or more of the following; guest speakers talking about issues related to the brain injured, a guest panel on community services, films, and discussion. The annual meeting, in addition, had elections for executive positions for the year to come. These meetings were informal with time at the end for coffee and talking with others.

Perceptions with regard to the roles of professionals in NABIIS varied. Three thought they were not involved enough and really did not have a large role to play. At the same time they were aware that professionals have limited time and energy to give. Generally, family members knew they were always there for support and information. Three people felt that it was mostly family members who were making NABIIS go but the professionals were a strong backup, provided structure, information, and direction. It was suggested that while professionals have their role, it was the family involvement that is vital. Professionals helped get the group started, now families can carry on, but they are always in the background and can be counted on when suport, ideas, or opinions are needed.

Two individuals thought they did give input but it was too clinical and hospital related, or they were inclined to quote the textbooks. It was suggested that in some ways their viewpoints were too shortsighted. They did not have any direct attachment to anyone with a head injury. They did not always listen well to what families had to say once to patient was at home.

One person felt the professionals were doing very well, were actively involved, and committed to NABIIS since they strongly felt the need for the group. She felt NABIIS had good cooperation and support from hospital staff. Finally, it was thought that although some professionals were involved, there was no involvement from physicians, and some NABIIS members would like to see them take a greater interest.

Outcomes

The most common response to how NABIIS has helped its members was support; having others to talk with, share problems with, knowing that they were each not alone with their problems. Other people understood without having to go into lengthy explanations. They knew exactly what one was going through. Even when extended family were not available for support, one could go to NABIIS and find that a stranger will care and understand. It helped family members accept what had happened. A second common answer was that it was a place to get basic information on how others are coping, information they had gathered regarding available programs and services in other cities. A third response was the involvement in trying to do something worthwhile about the difficulty, in trying to create new programs and facilities to offer others in the future. Two members commented on the feeling of accomplishment they felt every time NABIIS took a step forward feeling that their work was starting to pay off. A fourth was the personal satisfaction derived from helping other people experiencing more recent injuries. As well, this took attention away from themselves. It gave them something else to think about, somewhere to put their energy. A fifth benefit was the socialization aspect and the enjoyment of spending a nice social evening with friends.

Since joining NABIIS each felt more knowledgeable and more realistic about expectations. Some said that they had to lower their expectations for recovery, and one commented that in some ways she realized how lucky her family member was compared to some other injured persons. Being a part of the group made it easier to talk about the injury and understand some of the feelings, for example, shame and guilt, that may accompany it.

Although it was agreed that NABIIS was meeting the needs of its members, some limitations and possible improvements were mentioned. The primary limitation is lack of funds. Finances are needed to get facilities such as a rehabilitation center, a centre to provide day care and a retraining program and courses. To get this, it was suggested that they need more political clout and contacts. As well, an executive director is needed to oversee all that is happening, to insure that the group and its events would run smoothly and effectively, and to guide and steer the volunteers in a direction. As one person said, "there are too many Indians and not enough Chiefs". A profesional counsellor is needed as well to help families deal with their problems. This person would need to have a good understanding of the issues related to brain injury. One person suggested that NABIIS needs to incorporate a volunteer program to work with injured members on a one to one basis. It is also necessary to have members get involved with families immediately after the accident in the very early stages.

Two individuals suggested that there was nothing directed toward children and teenagers. NABIIS was primarily for young adults and adults with little attention paid to the needs of younger people. While they feel the effects of having a sibling or parent with a head injury, they are often left behind and neglected. Another suggestion was made in reference to the coffee houses. Two people felt that there should always be two separate meetings, one for injured persons and one for family members to allow for families to share more with each other. One suggested there should be three separate groups - one for victims, one for parents and spouses, and one for siblings and young children of injured persons. As well, the coffee house meetings should be a little more organized and have more leadership to facilitate discussion as a whole rather than having a few separate conversations going at once.

There was, as well, a recommendation for more socialization.

Three persons voiced a concern that the people who were so actively involved with NABIIS from the beginning were starting to tire out. More people are needed to share the responsibilities. There is a core of workers who do more than their share and are starting to resent the time they are putting in. Finally, public education is needed in terms of speakers going to schools, and presentations to government on the issues, concerns, and prevention of head injury.

C. Contributions to the Literature

From this descriptive study, a number of contributions can be made to the literature. The uniqueness of NABIIS stands out. There are few other resources in the country that provide the public service in the area of psychological support for head injured persons and their families that is offered by this group. They are leaders in the field of establishing the basis of a sound organization with alot of potential. Other groups can follow the lead in its structure, format, nature of support, professional involvement, and openness. They have, as well, made people aware of this local group as part of the community, its needs and its goals, in the rehabilitation of head injury.

In addition to the literature on self-help groups, this study contributes to the literature on families. It supports the theories of family systems and family involvement in the betterment of one of its members. Getting the family involved in the recovery process while providing support and encouragement along the way facilitates adjustment for both the family and the injured individual. As well, family therapists can become more aware of the impact of head injury on the system and provide guidance and direction for families requiring assistance.

The literature on group counselling points out how this technique differs from other group techniques (Ohlsen, 1977). However, results of the present study indicate that the criteria for group counselling and for a self-help group can have considerable overlap. Ohlsen (1977) outlined a number of features about group counselling. He suggested that it is based on a learning model, participants are encouraged to openly discuss their feelings, recognize their potential, to define goals, and change to desired new behaviors. Confidence is put into the participants ability to accept responsibility, and it is necessary to adjust and sometimes change their environment. Elements of group counselling include developing the relationship, discussion of feelings, defining behavioral goals, sharing successes, and growth. As professional counsellors facilitate group counselling, this has implications for potentially increasing their involvement in meeting the needs of self-help group members.

V. Conclusions and Implications

NABIIS appears to be a cohesive self-help group which is a source of help for many difficulties for its members. It offers a peer-model of providing support, aid, and information based on mutual identity. Through finding others who know and can understand, it encourages communication and other interactions, and provides access to others who can share their own experiences. This informal, secondary group satisfies both the socio-emotional needs of its members, as well as being task-oriented in terms of lobbying to raise funds for specific services and facilities.

Cohesiveness is a major factor in determining group performance (Freedman et. al., 1981, & Shaw, 1981). The more cohesive the group, the better members perform in cooperation, the more effective the group is. NABIIS had a few members who form a highly cohesive subgroup. However there are many members who have minimal participation in the larger organization. As well, the more the group can draw on an individual's resources, the more effective it is (Goldstein, 1980). If members are not actively participating and feel a lack of cohesiveness, their resources are not being tapped.

Through studying a self-help group in the area of head injury, the literature on the effects on a family was strongly supported. Family members indicated that the injury disrupted their lives in terms of existing roles and sharing between themselves (Blazyk, 1983), and isolation and abandonment by extended family and friends was evident (Lezak, 1978).

NABIIS fits in best with typologies offered by Tracy and Gussow (1976), and Gartner and Riessman (1977). It provides mutual aid and assistance to members in dealing with adaptive problems resulting from disability due to illness, disease, or other health related disorders often leading to residual impairment and chronic disability (Tracy & Gussow, 1976). NABIIS fits in with the "living with" groups. Meetings provide a sounding board for members to learn, to devise, to consider, and to test new methods of coping as well as to receive reinforcement for prior satisfying adjustments. Members express a sense of comfort in learning that their grief, pain, and everyday difficulties were not unlike those of others (Gartner & Riessman, 1977).

NABIIS clearly provides support, information and knowledge, and advice (Richardson & Goodman, 1983; Jaques & Patterson, 1974), personal sharing, educational, social, and recreational activities, and lobbying (Romeder, 1982), and a sense of belonging for group members (Jaques & Patterson, 1974). Reciprocity in terms of both giving and receiving help was also evident (Katz, 1981).

A number of statements can be made in response to the research questions. Firstly, with regards to the initial beginning of a group, a self-help group has the potential to develop if several people indicate a problem area and take an interest in working toward starting up a group. However, it appears that those who are actively involved in the early stages tend to maintain their involvement. Although new members are always joining, few become actively involved. As well, the primary goal the group set out to achieve was to provide support for its members.

Secondly, in terms of the nature and practices of the meetings, in the early years, the group's intent and observations are closely paralleled as members are making every possible effort to meet their goals. Meetings were informal gatherings allowing members to share ideas, information, and feelings

Thirdly, and most importantly, in reference to the adjustment process, members who maintain an active involvement feel the group is effective in satisfying their needs and can facilitate their adjustment to a novel situation.

As well, several post hoc hypotheses can be formulated. The nature of the self-help group, its interventions and support, can facilitate a healthy and satisfying adjustment through the learning of specific recovery and management strategies. Furthermore, through self-help groups, family members can assist the injured members to live up to their fullest potential given interventions in the home and family. With reference to environmental influences, as they too greatly effect recovery, active involvement from family members in designing therapeutic interventions is advantageous. Finally, the recovery mechanisms which family members may be able to utilize follow the functional adaptation theory.

It cannot be disputed that the recovery of functions following a brain injury is a complex process influenced by many factors. As family members of a self-help group, it is important to be aware of the pattern of recovery and the factors that influence the injury. Injured persons will differ in the time and extent of recovery.

Age, for example, is an important variable. It is well recognized that the effects of comparable lesions are not as drastic in children as in adults. Given comparable lesions, younger persons will show less behavioral disruption and less severe impairments, and will display better recovery (Golden, 1978). This is consistent with the Kennard principle which indicates better recovery in younger people (Miller, 1984). Therefore, family members who are dealing with younger injured members can utilize environmental manipulations to a greater effect than may be the case for older members.

Time is a second significant factor. Older skills are less affected and recover more quickly than recently acquired skills. This relationship is referred to as Ribot's Law (Miller, 1984). The longer the time elapsed from the acquisition of a skill to the time of the brain injury, the less likely it is to be disrupted, and, if disrupted, the better it will recover.

Handedness, intelligence, personality, motivation, general health, emotional state, and the extent and site of the lesion can effect outcome recovery as well (Golden, 1978; Miller, 1984). However, objective data are lacking, and more research is needed to determine the relationship between these variables and the recovery process.

There is evidence that environmental manipulations can have an effect on recovery which encourages the idea that psychological interventions may be of great value in the rehabilitation of brain injured persons (Miller, 1984). Furthermore, any interventions that influence the extent and rate of recovery will be more effective the closer they are applied to the time of the injury. This has been shown in an investigation carried out by Cope and Hall (1982). Those who entered active rehabilitation programs later needed twice as long before considered fit enough for discharge. Early therapeutic interventions are the most efficacious. As well, having to unlearn maladaptive strategies that have spontaneoulsy developed can be avoided.

As a self-help group is a form of environmental manipulation and is seen as a therapeutic intervention, it can be hypothesized that the sooner families and injured persons become involved with a group, the sooner thay can begin to learn and share with others and begin the recovery process. The injured person's family and significant others play major roles in the social environment. They can provide support and motivation, or sabotage recovery through indifference and reinforcement of the disability (Golden, 1978). Getting support and guidance early can be helpful in leading the injured member toward healthy recovery.

Three groups of recovery mechanisms have been postulated to explain the recovery process in a head injury (Miller, 1984). These are the artifact theories, anatomical reorganization, and functional adaptation. The different explanations are not necessarily mutually exclusive.

The artifact theories state that "the lesions will destroy certain tissue with the loss of those aspects of behavior for which the intact functioning of the destroyed area is essential" (Miller, 1984, p. 57). This primary deficit is generally permanent. In addition, temporary disturbances in the physiological functioning of other parts of the brain are produced and result in secondary behavioral impairments. Secondary deficits recover as the temporary disruption is resolved. Functions underlying these secondary deficits are repressed or inactivated rather than lost. Recovery is thus an 'artifact' in the sense that recovery implies that what has been recovered has been truly lost rather than inhibited or suppresed.

The second theory, anatomical reorganization, suggests that when "damage occurs to one part of the brain recovery can take place by means of other parts of the brain taking over the functions originally subserved by the damaged parts" (Miller, 1984, p. 59). This assumes some degree of localization of function.

The third theory is functional adaptation. This approach explains the reattainment of functions as goals rather than the recovery of the means by which goals are achieved. The injured person may be able to "relearn the ability to achieve a certain goal affected by neural damage by means other than those originally employed" (Miller, 1984, p. 60). For example, if one who uses tactile feedback to tie one's tie, and this skill becomes impaired, one can then try visual feedback to accomplish the same goal. Appropriate directed training may be of considerable value in enhancing adaptation following brain damage.

Two different goals of intervention can be described. The first, restitution, implies the full or partial recovery of functional capabilities. The second, amelioration, is a more limited goal and is concerned with assisting the injured individual to function as well as possible despite the disability. Amelioration is a much more potentially attainable goal than restitution for any psychological intervention directed at the management and rehabilitation of the brain injured (Miller, 1984). It is the goal of amelioration that family members of a self-help group can work toward achieving with their injured member. Group members can discover and share specific strategies to help the injured individual better function. Amelioration is best coupled with the functional adaptation theory of recovery.

Amelioration is directed toward practical things that families can do which are geared toward carefully selected target problems. For example, making lists as an aid for poor memory, finding alternative ways of reaching the same goal, adapting the environment to suit the needs of the injured person, and using imagery in verbal learning and retention. Behavioral techniques including anxiety reduction, as well as cognitive techniques such as problem solving tasks can be used in amelioration of resulting personality and behavior problems. Each intervention needs to be carefully selected for the needs of the individual.

A. Intent versus Observations

Bearing in mind that NABIIS is a young group, it clearly proves to be growing and moving in the direction that it was initially proposed for. Its intent and present observations are closely paralleled. Its basic philosophy and goals have not changed over time. The main focus was to provide support for families learning to live with and adapt to a head injury in one of its members. Participants all agreed that a main reason for joining the group was for support and understanding from others.

Members generally learned about the group from the source in which it got started - the rehabilitation hospital. There were few referrals from other agencies or organizations. This may be a function of the newness of the group. It may take more time before it becomes better known in the community. Secondly, some of the family members were injured and well on the way to recovery before the group existed. It is interesting to note that 100% of participants expected their membership to be permanent. This is in contrast to the literature that suggests that self-help groups are often temporary in nature.

NABIIS was quickly successful at achieving its primary goal - support. Other short term goals have been accomplished as well including providing a registry and a library. One long term goal of establishing a group in an outlying area has recently become a reality. The main hindrance to achieving some of its longer term goals is lack of funds. Providing a relief service, day care and housing arrangements, and educational and vocational programs requires much more financing than is currently available. Through continued increased public awareness, these too, may soon become a reality.

Participants were enthusiastic about their group's effectiveness and spoke very favourably about its role in their lives. For example, comments from family members included "I recommend it very highly to anyone as something worthwhile", and, "They are a very close group. You get a terrific feeling from them. They don't close any doors, keep an open mind, are willing to listen to you, and try anything." Although some suggested ways to improve it, no one had regrets about joining. It is necessary to keep in mind that this is a perceived effectiveness rather than objective effectiveness. Participants were those who remained in the group, attended meetings, and agreed to volunteer for this study. Others who have dropped out or were not very actively involved may have different perceptions.

In addition to the problem of needing money to expand its service, NABIIS faces a problem that is frequently referred to with reference to self-help groups. Most of the work load falls on a core group of people while many of the remaining members stay apathetic and uninvolved (Richardson & Goodman; 1983, Silverman, 1980). This core that carries the load gets physically and mentally fatigued and worn out. Some other members do participate to a limited extent.

B. Professional Involvement

Family members do not always find rehabilitation professionals the optimal source for providing emotional support and helping to solve the everyday problems imposed by the head injury and its consequences (Rosenthal & Muir, 1983). Members were not formally involved with other mental health professionals in the past, nor concurrently with being a group member. The extent of their use of professionals was assessment or informal discussions about how they were managing. However, most invited increased involvement from professionals and hoped for more participation from them, particularly from physicians. It can be speculated that the group is less threatening than comparable professional treatment, and the social friendly nature of a self-help group is preferred. No one was an active member of any other self-help groups, but a couple were involved with paternal groups.

Professionals were involved as founders, liaisons, consultants, and guest speakers. They did not actively participate in day to day activities, board meetings, or coffee houses. In agreement with Borman (1979), they played a key role as founders of the group and were instrumental in its early workings. This is contrary to much of the literature which suggests there is slight if any evidence of professional influence (Katz, 1981; Romeder, 1980; Tracy & Gussow, 1976). This may be due to the nature of NABIIS in that the area of brain injury and its consequences are difficult to understand, and any additonal help and information is appreciated.

C. Recommendations

Clearly, NABIIS provides an effective means for individuals to receive information, share mutual concerns, and offer supportive relationships. Its benefits include identification with the group, attainment of new referral systems, increased social skills, self-evaluation of progress, and increased motivation. However, some recommendations for improvement can be made which apply not only to NABIIS, but to other self-help groups as well.

Firstly, as this study illustrates, family involvement in self-help groups is advantageous and beneficial to family members in allowing them to adjust to the difficulty and helping them be more effective in dealing with the injured person. They stated that knowing more about the injury and gaining a better understanding helped them adapt to their situation. They want to be active participants. This should be kept in mind for other groups of a similar nature, particularly those where the family lives with the member on a day to day basis or has regular contact with the individual.

Secondly, it is advantageous to the individual and family that they be introduced to this type of experience early in the recovery and rehabilitation process. This allows the family to learn to deal with the injured member before problems become difficult to reverse. They could learn adaptive coping skills, specific interventions, and problem solving from others before the family system becomes too dysfunctional. This is supported by the literature (Cope & Hall, 1982).

Thirdly, with regard to the family support group, more structure, direction, and organization may be beneficial for specific problem solving. It would be more useful to deal with specific issues one at a time and have a focus for each session rather than jumping from topic to topic, or having more than one conversation going on at once. There was evidence that participants would have preferred more planning and structure. Suggestions include having films or guest speakers to talk on specific learning strategies and interventions on the variety of problems related to brain injury (Miller, 1984). For example, one session can be spent on dealing with improving memory through repetition and making lists, while another can be devoted to dealing with anxiety through learning relaxation techniques.

Fourthly, there is a need to get more people actively involved in running the course of the group. The core of workers tire of carrying the load. Many group members shared this perception and it is well supported in the literature (Richardson, 1984 & Silverman, 1980). One possible way to achieve this is to set up projects and committees to work on them. By getting more members involved, and by sharing the work load, group cohesiveness can increase as well.

Fifthly, particularly when the self-help group is formed to respond to needs related to physical or health problems, it is recommended that the individual maintain follow-up contact with the physician to monitor and evaluate progress or possible deterioration. This allows for the physician and family to work together toward the improvement of the injured person on all facets of life including physical, emotional, and behavioral.

A sixth recommendation is the need for public education and prevention (Ivan, 1984). For example, increased use of seatbelts and helmets, and a decrease in impaired driving can lower the incidence of head injury. Education as to the effects of the injury can alleviate the anxiety that surrounds the unknown and the unfamiliar and allow people to be more comfortable in dealing with the injured individual.

D. Limitations

As was previously mentioned, voluntary membership and participation may account for sampling bias. d to the family support group, more structure, direction, and organization ma at once. interviewed were typical or representative, they did include a range of involvement and experience both with the group and with the problem for which it was formed (Richardson & Goodman, 1983).

Some researchers are concerned with numbers of persons to be interviewed. For the present study, five founding members, and 10 family members were interviewed. It is the authors impression that this was sufficient. Many of the concerns, issues, and ideas were similar. This may be a result of the closeness of the group. Many members spent a great deal of time talking and sharing with each other.

E. Implications for Rehabilitation and Counselling

In early phases of the injury little information has been provided to the family about the expected sequelae, or to alleviate anxiety about the road ahead. The advantage of early contact with others experiencing similar injuries and with well informed hospital staff who are sensitized to their needs is apparent. It is during the early post hospitalization period that families try to accept permanent change in their injured family member, and adapt their own lifestyles to provide for the increased dependency needs of the affected member. The search for an adequate care setting often is their major preoccupation (Cole, Cope, & Cervelli, 1985). Participants commented on the lack of facilities and direction at the time they were experiencing the injury. The usefullness of being aware of the resources NABIIS has to offer on direction, and suggestions it can provide cannot be overestimated. As well, an early intervention screening and assessment procedure would allow for quick identification of services needed.

After discharge from hospital programs, brain injured individuals with physical, cognitive, or behavioral problems too severe to permit entry into existing educational, vocational, or recreational programs often return home without adequate support services provided for themselves or their families (Cole, Cope, & Cervelli, 1985). NABIIS is a strong step in the direction of providing these support services.

However, the need for specialized educational and vocational training in the community is paramount, yet sadly lacking. Only one injured person in this study was employed. Many others had attempted returning to work but were unsuccessful. Family members can help by providing information to employers about the brain injured, their perceptions, and behaviors. They can explain the injury, the consequences, and effects so employers can gain a better understanding. This area definitely requires more attention to facilitate reintegration into the community as active members. Government funding is necessary to realize this goal.

F. Suggestions for Further Research

One challenge is whether criteria used to assess the effectiveness and effects of this group can be generalized across diverse groups (Lieberman & Borman, 1976). Would reports by members of other self-help groups compare to those presented here? What would less active members say about how NABIIS effected them? What about those dealing with a head injury who chose not to join this group? In the present study, members were not receiving help from mental health profesionals. Would being a member fo a self-help group in addition to receiving psychotherapy or psychiatric help alter the perceived effectiveness of NABIIS? In reference to the effectiveness of specific interventions, the use of a single case experimental design would provide beneficial knowledge to treatment of neuropsychological impairments.

VI. Referencs

Annegers, J., Grabow, J., Kurland, L., & Laws, E. (1980). The incidence, causes and secular trends of head trauma in Olmstead County, Minnesota, 1935-1974. Neurology, 30, 912-919.

Berkowitz, L. (1980). A survey of social psychology. New York: Holt, Rinehart & Winston.

Bishop, D., Epstein, N., & Baldwin, L. (1981). Disabilities: A family affair. In D.S. Freeman & B. Trute (Eds.). Treating families with special needs, Alberta Association of Social Workers, Ottawa.

Blazyk, S. (1983). Developmental crisis in adolescents following severe head injury. Social Work in Health Care, 8, (4), 55-67.

Boll, T.J. (1981). Assessment of neuropsychological disorders. In D.H. Barlow (Ed.), Behavioral assessment of adult disorders. New York: Guilford Press.

Bond, M.R. (1975). Assessment of the psychological outcome after severe head injury. In R. Porter & D.W. Fitzsimmons (Eds.), Outcome of severe damage to the central nervous system: Ciba Foundation Symposium (vol. 34). Amsterdam: Elsevier.

Bond, M.R. (1983). Effects on the family system. In M. Rosenthal, E.G. Griffith, M.R. Bond, & J.D. Miller (Eds.), Rehabilitation of the head injured adult. Philadelphia: F.A. Davis.

Bond, M.R., & Brooks, D.N. (1976). Understanding the process of recovery as a basis for the investigation of rehabilitation for the brain injured. Scandinavian Journal of Rehabilitation Medicine, 8, 127-133.

Borman, L.D. (1979). Characteristics of development and growth. In M. Lieberman, & L. Borman (Eds.), Self-help groups for coping with crisis. San Fransisco: Jossey-Bass.

Bray, R.M., Kerr, N.L., & Atkin, R.S. (1978). Effects of group size, problem difficulty, and sex on group performance and members reactions. Journal of Personality and Social Psychology, 36, 1224-1240.

Brooks, D.N., & Mckinlay, W.W. (1983). Personality and behavioral change after severe blunt head injury-a relative's view. Journal of Neurology, Neurosurgery and Psychiatry, 46, 336-344.

Bruyn, S.T. (1966). The human perspective in sociology. The methodology of participant observation. Englewood Cliffs: Prentice-Hall.

Calhoun, D.W. (1976). Persons in groups: A humanistic social psychology. New York: Harper & Row.

Campbell, D.T. (1978). Qualitative knowing in action research. In M. Brenner, P. Marsh, & M. Brenner (Eds.), The social contexts of method. London: Croom Helm.

Caplan, G., & Killilea, M. (1976). Support systems and mutual help. Multidisciplinary explorations. New York:

Grune & Stratton.

Cartlidge, N., & Shaw, D.A. (1981). Head injury London: W.B. Saunders.

Cole, J.R., Cope, N., & Cervelli, L. (1985). Rehabilitation of the severely brain-injured patient: A community based, low-cost model program. Archives of Physical Medicine and Rehabilitation, 66, 38-40.

Cope, D.N., & Hall, K. (1982). Head injury rehabilitation: Benefit of early intervention. Archives of Physical Medicine and Rehabilitation, 63, 433-437.

Cronbach, L.J. (1982). Designing evaluations of educational and social programs. San Fransisco: Jossey-Bass.

Cronholm, B. (1972). Evaluation and mental disturbance after head injury. Scandinavian Journal of Rehabilitation Medicine, 8, 35-38.

Dikmen, S., & Reitan, R.M. (1977). Emotional sequelae of head injury. Annals of Neurology, 2, 492-494.

Dornan, J. (1985a). The long-term sequelae of head-injury: I. Modern Medicine of Canada, 40, 244-258.

Dornan, J. (1985b). The long-term sequelae of head-injury: II. Modern Medicine of Canade, 40, 484-500.

Freedman, J.L., Sears, D.O., & Carlsmith, J.M. (1981). Social psychology. New Jersey: Prentice-Hall.

Friedman, W.A. (1984). Head injuries. Clinical Symposia, 36,(1), 2-32.

Gartner, A., & Riessman, F. (1977). Self help in the human services. San Fransisco: Jossey-Bass.

Gartner, A., & Riessman, F. (1982). Self help and mental health. Hospital and Community Psychiatry, 33, 631-635.

Glaser, B.G., & Strauss, A.L. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine.

Goethe, K.E., & Levin, H.S. (1984). Behavioral manifestation s during the early and long-term stages of recovery after closed head injury. Psychiatric Annals, 14, 540-546.

Golden, C. (1978). Diagnosis and rehabilitation in clinical neuropsychology. Springfield: Charles C Thomas.

Goldstein, J.H. (1980). Social psychology. New York: Academic Press.

Griffith, E.R. (1983). Types of disability. In M. Rosenthal, E.R. Griffith, M.R. Bond, & J.D. Miller (Eds.), Rehabilitation of the head injured adult. Philadelphia: F.A. Davis.

Gust, T. (1979). Psychological impact of head injury upon the patient's family. Paper presented at an international seminar on the rehabilitation of the traumatic brain injured adult, Toronto.

Hill, K. (1983). Helping you help me: A guide book for self-help groups. Health and Welfare Canada, Ottawa.

Hirsh, B.J. (1980). Natural support systems and coping with major life changes. American Journal of Community

Psychology, 8, 159-172.

Hollander, E.P. (1981). Principles and methods of social psychology. New York: Oxford University Press.

Hpay, H. (1971). Psycho-social effects of severe head injury. In Head injuries. Procedings of an international symposium. Edinburgh: Churchill Livingstone.

Isenberg, D. (1981). Coping with cancer: The role of belief systems and support in cancer self-help groups. Doctoral Dissertation, Northwestern University, Illinois.

Ivan, L.P. (1984). The impact of head trauma on society. Canadian Journal of Neurological Sciences, 11, 417-420.

Jaques, M.E., & Patterson, K.M. (1974). The self-help group model: A review. Rehabilitation Counseling Bulletin, 18, 48-58.

Jennett, B. (1983). Scale and scope of the problem. In. M. Rosenthal, E.G. Griffith, M.R. Bond, & J.D. Miller (Eds.), Rehabilitation of the head injured adult. Philadelphia: F.A. Davis.

Jennett, B., & Teasdale, . (1981). Management of head injuries. Philadelphia: F.A. Davis.

Karpman, T., Wolfe, S., & Vargo, J. (in press). The psychological adjustment of adult clients and their parents following closed head injury. Journal of Applied Rehabilitation Counseling.

Katz, A.H. (1981). Self help and mutual aid. An emerging social movement? Annual Review of Sociology, 7, 129-155.

Katz, A.H., & Bender, E.I. (1976). The strength in us. Self-help groups in the modern world. New York: New Viewpoints.

Knight, B., Wollert, R.W., Levy, L.H., Frame, C.L., & Padgett, V.P. (1980). Self-help groups: The member's perspective. American Journal of Community Psychology, 8,(1), 53-65.

Lazarus, L.W., Stafford, B., Cooper, K., Cohler, B., & Dysken, M. (1981). A pilot study of an Alzheimer patient's relatives' discussion group. Gerontologist, 21, 353-357.

Lenrow, P.B., & Burch, R.W. (1981). Mutual aid and profesional services: Opposing or complementary? In B.H. Gottlieb (Ed.), Social networks and social support. Beverly Hills: Sage.

Levy, L.H. (1976). Self help groups. Types and psychological processes. Journal of Applied Behavioral Science, 12, 310-322.

Lezak, M.D. (1978). Living with the characterologically altered brain injured patient. Journal of Clinical Psychiatry, 39, 592-598.

Lieberman, M.A., Bond, G.R., Solow, N., & Reibstein, J. (1979). Effectiveness of women's consciousness raising. In M.A. Lieberman, & L.D. Borman (Eds.), Self-help groups for coping with crisis. San Fransisco:

Jossey-Bass.

Lieberman, M.A., & Borman, L.D. (1976). Self help and social research. Journal of Applied Behavioral Science, 12, 455-463.

Lieberman, M.A., & Gourash, N. (1979). Effects of change groups on the elderly. In M.A. Lieberman, & J.D. Borman (Eds.), Self-help groups for coping with crisis. San Fransisco: Jossey-Bass.

Lindgren, H.C. (1973). An introduction to social psychology. New York: John Wiley & Sons.

Lishman, W.A. (1973). The psychiatric sequelae of head injury: A review. Psychological Medicine, 3, 304-318.

Mauss-Clum, N., & Ryan, O.K. (1981). Brain injury and the family. Journal of Neurosurgical Nursing, 13, 165-169.

McDavid, J.W., & Harari, H. (1974). Psychology and social behavior. New York: Harper & Row.

McKinlay, W.W., Brooks, D.N., Bond, M.R., Martinage, D.P., & Marshall, M.M. (1981). The short term outcome of severe blunt head injury as reported by relatives of the injured persons. Journal of Neurology, Neurosurgery, and Psychiatry, 44, 527-533.

McNeny, R. (1983). Deficits in activities of daily living. In M. Rosenthal, E.G. Griffith, M.R. Bond, & J.D. Miller (Eds.), Rehabilitation of the head injured adult Philadelphia: F.A. Davis.

Middlebrook, P.N. (1974). Social psychology and modern life. New York: Alfred A. Knopf.

Miller, E. (1979). The long-term consequences of head injury: A discussion of the evidence with special reference to the preparation of legal reports. *British Journal of Social and Clinical Psychology, 18,* 87-98.

Miller, E. (1984). *Recovery and managemment of neuropsychological impairments.* New York: John Wiley & Sons.

Newcomb, F. (1982). The psychological consesquences of closesd head injury: Assessment and rehabilitation. *Injury, 14,* 111-136.

Newcomb, T.M., Turner, R.H. & Converse, P.E. (1965). *Social psychology.* New York: Holt, Rinehart & Winston.

Oddy, M., Humphrey, M., & Uttley, D. (1978). Stresses upon the relatives of head injured patients. *British Journal of Psychiatry, 133,* 507-513.

Ohlsen, M. (1977). *Group Counseling.* New York: Holt, Rinehart, & Winston.

Panting, A., & Merry, P.H. (1972). The long term rehabilitation of severe head injuries with particular reference to the need for social and medical support for the patient's family. *Rehabilitation, 82,* 33-37.

Pearson, R.E. (1983). Support groups: A conceptualization. *Personnel and Guidance Journal, 61,*(6), 361-364.

Richardson, A. (1984). *Working with self-help groups. A guide for local professionals.* London: Bedford Square Press.

Richardson, A., & Goodman, M. (1983). *Self help and social* care: Mutual aid organizations in practice. London: Thetford Press.

Rinehart, M.A. (1983). Considerations for functional training in adults after head injury. Physical Therapy, 63, 1975-1982.

Romano, M.D. (1974). Family response to traumatic head injury. Scandinavian Journal of Rehabilitation Medicine, 6, 1-4.

Romeder, J.M. (1982). Self help groups in Canada. Health and Welfare Canada, Ottawa.

Ron, A., & Najenson, T., & Mendelson, L. (1977). Development of comparative methods of evaluating rehabilitation after cerebro-cranial injury. Scandinavian Journal of Rehabilitation Medicine, 9, 141-146.

Rosenbaum, M., & Najenson, T. (1976). Changes in life patterns and symptoms of low mood as reported by wives of severely brain injured soldiers. Journal of Consulting and Clinical Psychology, 44, 881-888.

Rosenthal, M., Griffith, E.G., Bond, M.R., & Miller, J.D. (1983). Rehabilitation of the head injured adult. Philadelphia: F.A. Davis.

Rosenthal, M., & Muir, C.A. (1983). Methods of family intervention. In M. Rosenthal, E.G. Griffith, M.R. Bond, & J.D. Miller (Eds.), Rehabilitation of the head injured adult. Philadelphia: F.A. Davis.

Shaver, K.G. (1981). Principles of social psychology.

Cambridge: Winthrop Publishers.

Shaw, M.E. (1981). Group dynamics. The psychology of small group behavior. New York: McGraw Hill.

Silverman, P.R. (1980). Mutual help groups. Organization and development. Beverly Hills: Sage.

Stake, R.E. (1967). The countenance of educational evaluation. Teacher's College Record, 68,(7), 523-540.

Stang, D.J. (1981). Introduction to social psychology. Monterey: Brooks/Cole.

Thomsen, I. (1974). The patient with severe head injury and his family. Scandinavian Journal of Rehabilitation Medicine, 6, 180-183.

Tobis, J.S., Pure, K.B., & Sheridan, J. (1982). Rehabilitation of the severly brain injured patient. Scandinavian Journal of Rehabilitation Medicine, 14, 83-88.

Tracy, G.S., & Gussow, Z. (1976). Self help health groups: A grass roots response to a need for services. Journal of Applied Behavioral Sciences, 12, 381-396.

Vargo, F.A. (1984). Adaptation to disability by the wives of spinal cord males: A phenomenological approach. Journal of Applied Rehabilitation Counseling, 15,(1), 28-32.

Videka, L.M. (1979). Psychosocial adaptation in a medical self-help group. In M.A. Lieberman, & L.D. Borman (Eds.), Self-help groups for coping with crisis. San Fransisco: Jossey-Bass.

Walker, A.E. (1972). Long term evaluation of the social and family adjustment to head injury. _Scandinavian Journal of Rehabilitation Medicine, 4,_ 5-8.

Williams, R. (1979). Criteria for competence. _Psychological Reports, 44,_ 167-187.

Wolfe, S. (1984). _The role of problem solving in the long term readjustment of closed head injured adults._ Unpublished doctoral dissertation, University of Alberta, Edmonton.

Wright, B.A. (1983). _Physical disability - A psychosocial approach._ New York: Harper & Row.

Wrightsman, L.S., & Deaux, K. (1981). _Social psychology in the 80's._ Monterey: Brooks/Cole.

Appendix A

Consent Form

I voluntarily consent to participate in a study as described and conducted by Terry Karpman on the effects of a self-help group for head injured and their families. I understand that sessions will be tape recorded, used solely for research purposes, and that the tapes will be erased when the research project is completed. As well, I understand that the information given by me will be treated as confidential. I will not be identified by name and all identifying information will be removed.

Date

Signed

Witness

Appendix B

Questions for NABIIS members:

Demographic Data

Family member -

- age
- marital status
- number of children, ages
- occupation - Are you presently working outside the home? Were you working before the injury occurred?
- education
- Do you make use of any outside services ? e.g. home care
- relationship to injured person

Injured person -

- age
- date of accident
- Does he/she work outside the home?
- Was a financial settlement received after the accident?

Contact and entry (antecedents)

- When and where did you first learn about NABIIS?
- How long have you been a member?
- Did you consider your membership to be temporary or permanent?
- Why did you decide to join the group?

Involvement (transactions)

- How often do you attend meetings? Which ones?

How do you contribute to NABIIS? e.g. board member, family support group, BINGO, newsletter...

Evaluation (outcome)

How has the group benefitted you?

Did the group change the way you viewed the difficulty with which you were concerned?

What specifically was done by the group in order to help you?

Are there any limitations?

In what way can NABIIS be improved?

Relation to other helpers

Have you received help from a mental health professional as a direct result of the injury in the past? e.g. social workers, psychiatrists, psychologists...

Are you seeing a professional in relation to the problem surrounding brain injury at the current time?

What role do professionals fill with respect to your group?

What is the extent of their involvement?

Have you been a member of any other self-help group other than this one?

Do you have any other information that you would like to add to give me a better understanding of your membership in NABIIS?

Questions for NABIIS founders regarding intent:

Antecedents

Who initiated the organization of NABIIS?

How many people were at the first organizationaal meeting.

What was your role in getting NABIIS off the ground?

Why was NABIIS started?

What steps were taken to start the group?

Transactions

What was the role of professionals?

How was it funded?

How were members recruited?

What was the groups purpose?

What was anticipated to be the course of the group?

e.g. meetings, fund raising...

Outcome

What was the group supposed to acomplish?

What were the groups goals? (long term, short term)

What effect was it to have on its members?

Has the group evolved or changed over time? If so, how? e.g. membership, goals,...

Have there been any recurring problems?

Do you have any other information that you would like to add to my understanding of how NABIIS got started?

Appendix C

Chronological Development of NABIIS

November, 1982 - First organizational meeting.

May, 1983 - First board meeting.

July, 1983 - Incorporated as a society and named NABIIS.

December, 1983 - First coffee house. (Initially, too many people showed and it was difficult to talk. Then, in early 1984 no one showed up and consequently, they faded away. In the fall of 1984 they began again and are successfully continuing today).

March, 1984 - First BINGO.

June, 1984 - Rented office space.

September, 1984 - Hired first office employee - program co-ordinator.

June, 1985 - First annual Brain Injury Public Awareness Week.

September, 1985 - Hired executive director.

November, 1985 - Moved to larger office space.

Appendix D

I: *Interviewer*

P: *Participant*

I Who initiated the organization of NABIIS?

P It grew out of a family education group that I was running at the hospital as part of the brain injury program. We had set up a family education program for basically family members, friends, spouses, interested people to...and these were people who has a relative or friend up in the head injury units. So when the brain injury program started, we started the family education program, and out of that very quickly came requests for, hey, we should get together on a regular basis or we should...you know, are there any services, are there any support services outside of the hospital for brain injured people. Those kind of questions started coming up. Things like, hey, the Multiple Sclerosis people have a society. And there's all kind of societies for disabled kinds of people and yet the people with brain injuries have very special problems. Oh, for a number of reasons. And, so then, out of that came the idea well, maybe I should just see if I can get a group of people together who look like they'd be people who had enough energy left - after all the trauma they've been through - who have enough energy left, who have enough ingenuity, who have enough commitments, so that we can start up something like this.

I Were you doing the family education series on your own?

P Well, I was...I set it up. I acted as a sort of a host or chairperson or something like this. And I sort of was a coordinator for that thing for a couple of years. But the brain injured had a series of successions where I would start the series with something on the brain and brain injury and that sort of stuff. What happens to a person with brain injury, in sort of a general way. And then the physiotherapists and occupational therapists would take the nest session and talk about rehab. The speech pathologist and myself would take the next session on communication disorders and communication problems.

I That's the five-week series that's running now?

P Yeah, we had six at that time. And we've gone through...but it's out of that that people...and there were certain people that said, we'd really be interested in starting one of those. The key person to that at that time was probably A.B. She...her husband had been...well, I should just back up a little bit. There was...while this was going on here, at another hospital, Dr. B.B., there, had also gotten a group of people together and they were meeting together once in awhile, once every two months or so, to discuss, they'd bring in a speaker and these were all, again, around head injuries. So what we decided to do was to see if what was going on here in the family education thing, and what was going on there with B.B. could be combined into something. And so that was sort of a...so I went over there and sat in on...gave a presentation over there...and sat in on one of their sessions. We talked about things. That was back in '82. Yeah. The fall of '82. So, from that group, plus people from here, we sort of had in November of '82, that's a long time ago. In November of '82 we had a meeting here at the hospital and it was anybody that was interested. And what we did was personally contact the people we knew had at that time a brain injured person in their family and some of the brain injured people themselves and said, look, if you're interested in forming an association, come, and so that first meeting was in November of '82. And it was really kind of nice because we had an open, fairly large room downstairs. And about 50 people showed up. And it just blew my mind. So that was the beginning of it. I should give you the names of some of the people that were at the very early stage when it evolved besides myself. L.M. is the other person in the hospital here. You've talked to L. Yeah, O.K. She is the other person in the hospital here who was at that first meeting right away and was really keen and in many ways has carried an incredible load, an organizational type of load, for the whole two years since then. She's carried a tremendous amount of stuff. I don't know where she gets her energy, but that's alright. What we decided to do is set up a committee of people who would then organize the thing. And I'll give you those names. The chairman of that committee...by the way, I refused to become chairman of that committee. I refused to...I chaired that first sort of session but I decided not to take the leadership in the formation of the association itself except in a background level, because it was my idea that this thing isn't gonna go if it's gonna depend on professional people to run it. So I...they said, well, H., why don't you do it? And I said no. If you guys are interested, you have to do it. I'll back you as much as I can. I'll give you all the backing I've got. But there's no way I'm gonna do it because then you're gonna lean on me. It's gotta be you people that do it. Because my needs as a professional in the field are different than your needs as a family member. And the thing has to focus on the family members. So that's the way it happened. It was tempting...it was tempting to go ahead and take over simply because I know that these people are tired. They deal with crisis after crisis in the family all the time. And for many of them, they just don't have the energy to put into organization kinds of things. They don't have the energy to do self-help stuff. So the temptation was there very strongly fo me to say, o.k., I'll do the self-help stuff for you, which is, of course, totally contradictory. And so I didn't. But the people that were there and who were elected sort of as a group was R.G. who has a son with head injuries...have you talked to R.? Yeah, he's one you should talk to. He's backed out, he's now no longer on the board. But he was chairman of the board. He was chairman of the initial planning committee and one of those people who has just so much energy and then he has to back off. And that's the way it is with this kind of organization. Real good guy. Nice man. And besides, he's also a single parent with a son who is now 20, I suppose now 20ish, who had a head injury and a farmer in the Ponoka area. B.M. - he was here this morning. I was hoping he would kind of stick around and I'd introduce you to him.

I Oh, I know him from the meetings.

P Good. Another real fireball...a guy who is an eternal optimist. Incredible. And there's A.B. whose husband has a head injury. And again, she's one incredible lady. Like, these people, all of these people...L.M. I've mentioned. Also, for the...from the hospital here is H.W. who is involved...she's heavily involved...who is a head nurse on the ladies head injury unit, who was at that time but she isn't anymore, but who decided what she...that one of the things the group needed was some liaison between hospitals and stuff like that. And she decided to look after that. And B.B. was involved. Not very actively involved. He wanted to be involved but he couldn't. Just because of the pressures he was experiencing at that time. I was on the group, decided to stay on the group, sort of a consultant, or ad hoc, or whatever you want to call it. And then there was a fellow, B.M., who worked, and who decided that he...he's one of the few in the group who basically has nothing to do with a head injury personally, except on a sort of...it was a far relative or a friend of a relative or something like that who had a head injury and had gotten interested in it but who doesn't have one in the immediate family. The only one who wasn't either directly working with head injured people or who doesn't have one in the family. And he's done some invaluable work in the organizational kind of thing.

I L.M., she's a physiotherapist?

P She's a physiotherapist in the hospital.

I There seems to be a mixture between the professionals and the family members.

P Yes. And that was the idea. And the idea was to as much as possible to provide that mixture to start with and then the rest of us slowly pulled to the background as the family members would pick it up. And, as a matter of fact, I'm not officially on any board any more. I'm still a member. But I'm just in the background.

I The only one on the list that I haven't met is R.

P Okay. Nice guy. So the first sort of organization meeting was in November, I guess of '82. And from then on we've had a number of meetings and we decided to call ourselves a Brain Injury Interest Group. And later had to change our name because, to get registered under the Societies Act in Alberta, there has to be a...a charitable society has to have a descriptive name which includes area, geographical area and stuff like that. So then we started throwing around a whole bunch of things and it became the Northern Alberta Brain Injury Interest Society. Somehow or other it sounds a little bit better than BIIG.

I That's true. It does. That was in July of '83?

P That was in July of '83 that I think the thing actually became NABIIS. I have looked for my file. And all I've got is the newsletters. I don't have my file at all anymore on the...I can't remember what happened. I can't figure out what's happened, the history, the historical stuff. Like the first minutes of meetings and stuff like that. I can't find it. I suspect it's still somewhere in my file drawer. But I have the feeling that I lent it out to somebody...

I And didn't get it back.

P And didn't get it back. Because I kept all the minutes of the initial meetings and stuff like that. I wonder if L.M. has that stuff. I think I gave it to her.

I I can ask her.

P But I can't find it. And I know I kept very close track because I thought, if this goes, if this thing flies, people are gonna want to know exactly who was involved, when and how it happened. Eventually someone's gonna want to find out about it. And I saved all that stuff.

I It's around somewhere.

P So it was in July of '83 that we incorporated under NABIIS, under the name NABIIS. And then the board members were in fact the same people, pretty well the same people that had formed the initial board. I think that was basically what it was. The first newsletter was pretty coarse.

I Yeah, I think I have a copy of all those newsletters.

P This sort of stuff. Hand-written corrections all...it's coming, its' coming. R.R. was also involved very early on. He's a social worker here. But always until recently was involved just as a member. And then became a board member last year. So what we've done, we've tried to do, is keep it the key positions would be held by family members, professionals people from the hospital or other places, who are interested, can also be members of the board but... it's unwritten...but it's definitely a policy that it's a family group. And those of us who are professionals in the area who want to support the family group, fine, but don't take over.

I Yeah, the president and vice-president are family members. I know L. was secretary for quite awhile there. The new secretary is.

P Yeah. And that's the way it has to stay.

I Why was NABIIS started? I think you alluded to it a little bit...

P It wa started primarily because the people, the family members of head injured people, felt isolated from each other. So one of the things that they wanted to do...well, this thing of, you know, of, they meet somebody else with a brain injured family member. Finally, somebody they could talk to who understood what they were talking about. That was a very key factor. And so it was to provide mutual support and encouragement anad all that sort of stuff. And I think basically that was sort of, that's where it started. But the other thing that started it was...is that community facilities for people with brain injuries just don't exist, basically. There are facilities for a lot of disability groups. There are facilities for general, people who are generally disabled, that sort of stuff. There are no facilities for people with brain injury. And many people with brain injury have very specific kinds of needs that just cannot be met in other situations. So part of the idea behind starting NABIIS was to see if they could do some...eventually establish some specific resources for people with brain injury.

These might be an educational program, it might be vocational training program, it might be...almost anything so to help the people with the brain injury themselves, to have the kind of facilities that they need to get back on the road as far as they could go. So that was the second thing. As far as, you know, sort of government and medical establishment is concerned, the brain injured people were classified under mentally ill, or the mentally retarded, or the crippled and the physically disabled. And for some, brain injury is neither one of those, none of those. And so the facilities have been set up to deal with disabled people and to help disabled people, or to house disabled people or whatever were geared to those three main categories. And brain injured people...many of them didn't...some of them fit...but very few. Many of them just didn't fit at all. So that was the idea. O.K. See if we can actually begin to establish some specific programs for people with head injury. The third reason was...and it sort of comes out of the second one is that, hey, I don't think...or, we didn't think that the general public, the government or even the medical profession was really aware of what head injury was all about. So it was a PR function. It was a PR thing. And public awareness. There are such people that have had head injuries, that come in all kinds of shapes, sizes, have all kind of different disabilities and have all kinds of abilities at the same time. They're not write-offs. They're real people. And they're real people quite different from somebody who's mentally retarded, somebody who's mentally ill, or somebody who is just crippled. So it was just that sort of a thing. That sort of a thing sums it up. There were some other sort of applied things that came out of it. One of them was, all of them...without a single exception...talked about the incredible dread and fear that they felt when they were sitting in the hospital and their relative was in ICU - or intensive care unit - and nobody would tell them what was going on. Nobody could tell them what was going on. Nobody could say what was really the matter. Nobody could give them any idea of what might happen. Now...there's a number of factors here. I suspect that one of the factors is that people maybe try to tell them, but the people weren't listening. O.K. They were so shocked at that stage they weren't listening to anything. But my suspicion is that maybe they did try to tell them but probably tried to tell people in a whole bunch of jargon words and so that in fact they couldn't hear what was being told. You know, they have a large subdural hematoma on the parietal occipital lobes on the left side and chances of them making it aren't very good. Those were the kinds of things they were told. And it doesn't mean a bloody thing.

I Sure.

P So one of the things was....and that's sort of a spinoff of some of these other things...was to say, hey, look, maybe NABIIS can provide a volunteer service to serve as an emergency, emergency room...what's the word used. I've forgotten the word. We had a label that was kind of neat. But anyway, the idea was basically, you know, that when we find out that somebody has been admitted to one of the major hospitals with a severe head injury that somebody who's been through the thing, go up there, and talk to the people and talk with the people.

I In their own language.

P In their own language. Yes. Because even the people that are here now that have been coping with this for years, they don't talk in jargon. They talk about, you know, Joe doesn't remember anything. Joe gets mad when this happens. You know, that's the language they talk. They don't talk about...they don't talk jargon.

I Sure.

P So...that...there are spinoffs like that now. One of the other things that was really...one specific project that we tried to get off the ground and it didn't work was to get a training program started, a rehab, out of hospital rehab training centre started.

I But you're still trying.

P But, what the problem wass there, we started much too early. O.K. And we were jumping the gun. And basically, nobody was ready. And so it's just a matter of doing it again.

I That's more of a long-term goal?

P Yeah, that's more of a long-term goal. And we were still jumping the gun a bit and too enthusiastic. And I think that's basically the reasons why it started.

I O.K. What steps were taken to start the group? I think you already talked about that...

P Yes, we talked about that.

I The role of professionals. I think you mentioned that too.

P Yeah, and it's basically supportive.

I Supportive.

P Yeah, they have to have...these people are dealing with a family situation. That's what they deal with. That's the level that they're dealing with. Like, I'm a husband of somebody who was head injured or my wife is head injured and I have to deal with this and this and this. And I don't know what to do about it. And I do depend on the professional people to help set some direction because I'm basically lost. But if they come up with directions, you know, these are possibilities, these are things that are happening in other places and then I can say, oh, yeah, this is something that will work for me. Let's go in that direction. And they still have to make the choices. But they need that information and there's a lot of the professional role that is information giving, supplying the information, supplying them with back-up that way, and also supplying them, really backing them up emotionally as well. It's...many of these people feel like that their relatives have been just dumped back on them and society has said, to hell with it, you know, we can't do anything anyway, and they feel like...and it's really important that professional people be involved as a supportive, emotional support.

I Sure. They're getting their family members back and now what do we do with them? How was NABIIS funded at that time, when you were just getting off the ground?

P O.K. It was funded by two main groups. Number one was the hospital. What happened basically is that the hospital...I went to Dr. M. I said, hey, listen, we wanna get this group started and what we need is, we need a room and we need some paper and we need some facilities and we need some coffee and stuff like that. And he says, o.k., go ahead. So basically, the initial funding was straight from the hospital. I don't know how that...no, that was officially recognized. I remember sending a letter to Dr. M. saying, thank you and all that sort of stuff. Yeah, that's what it was. And still largely, the major expenses are..not now anymore but the first year, two years, that was all hospital funded. Like, we used hospital typists, we used hospital paper, we used hospital duplicating equipment, we used hospital coffee. We used hospital rooms, facilities, AV equipment. The whole business. But that was all very unofficial. That included things like typing, typists, and stuff that. Which is really neat. Because we couldn't have done it otherwise.

I Yeah, right, for the starting stages anyway.

P And then, of course, we started collecting some money from the other funding, fund-raising stuff. But the group was very determined they weren't gonna suck off the hospital for very long. That was really neat. Like, immediately, they said, yeah, well, this is nice but they weren't gonna be happy to just stay there. They were very determined and very quickly they were gonna start raising their own money. So, I think that says something about the kind of group they are. They aren't a bunch of dependent people. They're a very independent group.

I Well, some of the members now, their ideas are just so creative. They just keep going.

P Yeah.

I Some of the board meetings are very interesting. Some of things that they come up with. How were members recruited in the early phases?

P Word of mouth only. Basically what we did...

I Family education series...

P Through the family education series. Through...some of the people that were involved in the early stages were from some of the other hospitals. A couple from the hospital who were interested and they were sort of in there on the sidelines and were really interested and supportive. So they would...when they worked on the neuro wards over there or neuro programs over there and they'd say, well, hey, why don't you go... so they'd let people know. Basically it was work of mouth. Friends of friends. We went through our records here. Families with head injuries and contacted the families and say, here it is. That's how it started.

I And it still is going that way.

P And it's basically still going that way. I think that's the only way. Now there is going to be a sort of a head injury week next month or something like that. But word of mouth is still the way to go.

I What was the group supposed to accomplish? Again, go back to the early phases. I think you mentioned the main things that got it off the ground.

P What it was supposed to accomplish to start with is to just give the people, mainly family members, families, it's not just the victim,
to give the brain injured families a sense of community. You can go from there in all kinds of different directions, but give them an identity.

I That was the initial purpose. Then from there you talked about the resources, facilities...

P Yeah, and then started talking about making some sort of impact on the community one way or another. But the real motivation initially, what it was supposed to accomplish was a realisation that we are not the only family with this kind of problem, the kind of situation we have to deal with and if there is another family that has the same situation they have to deal with, maybe the two of us can get together and talk about it. That's where it started. Any other things were secondary. We need specialized facilities, we need this and that, but that was all secondary. The impetus came from, hey its so neat to talk to another family who has the same problem. That was it.

I Can you differentiate for me the short term goals from the long term goals? Short term was to give support to family members.

P The biggest most long term goal that there is, is to actually end up with a facility specialized in long term rehabilitation for people with brain injuries, and it would be a community facility. It would not be a hospital facility. That was one of the things. We don't want it run by the hospital, we don't want it run by the government, and we don't want it run by the school board because it would be run by the same kinds of rules as everything else is run by, and people with head injuries have special needs. But that's the long term.

I What effect has NABIIS had on its members? You mentioned support.

P Alot of encouragement and support. Like, we are not alone and we are not helpless. We are not totally helpless. It's very lonely when your family is in a situation that no other family really knows about. But it's very lonely. And when you get lonely you get discouraged and when you get discouraged you give up. The idea is to reverse that process.

I Do you think the group has evolved or changed over time in terms of membership, or goals? Or has it remained pretty constant. I realize it is not that old a group, only three years.

P No, its basic philosophy and long term goals and things that are important for us to do, there has not been much of a change. It is pretty consistent. Membership has grown. We started out with 40 or 50 people, and of course from the initial meeting some dropped out. No we are not interested in it, and then the next meeting we had after that was a real let down. The first meeting was about 50 people, the second meeting we had a month later there was only about 25 or so. I thought, gosh. But out of those 25 were the key people who were to become the first board members and they were really great people because they were the ones who really wanted to stay. Alot of the ones who came initially were just curious.

I Try it out for once and then see.

P Yeah, and then decided no, this would not meet my needs or there is no way I could invest the time or energy that is required to get this going, or their own legitimate reasons. But I was very disappointed. I had visions of, the first one had 50 people, the next 100, not the other way, 50 to 25.

I At that time you were thinking of establishing groups in other areas as well. Is there a bit of that happening?

P Yes. Right. One of the real important things about us is the family mutual suport and local action. It is very difficult for me if I live in a town here to be supportive of someone in Peace River or in Drayton Valley or Vermillion. So one of the very early goals was to set up, to have the association, Northern Alberta, but then to set up local groups, chapters for mutual support and PR. That would be the two main functions of local groups. They would be able to get together once in awhile and bring in a speaker, or just get together for coffee and discuss things informally. Where as a local area they could perhaps put some pressure on certain recreation and social service agencies. Hey, look, there is a bunch of people up here with a head injury and this is what we would like, which are things that can't be done from Edmonton or a central location. They have to be done locally. Like if I know the mayor of the town and I could say there is so and so in the area and we need something.

I Has that happened? Are there any other?

P It is starting to. There are movements in Grand Prairie/Peace River. They are deciding if they will become one local area or are going to go two. I think they will probably go two. There has been movement in St. Paul. Those are the two.

I Last question. Have there been any recurring problems?

P Fatigue. Main problem. Absolutely the main problem is fatigue. Those of us who are staff members are working with brain injured people all the time. We are at that same time working very hard in getting the treatment program here, the rehab program in the hospital underway and firming that up and establishing that and setting directions for that. So many of us did not have an awful lot of extra energy. The family members who got involved were people who were dealing with the crisis at home from day to day, or at the hospital. So that was the main problem.

I Is there anything you would like to add? Anything that can give me an idea of how NABIIS got started? I'm looking at initial intentions.

P The major barrier that NABIIS had to cross which was part of the initial intent was to make government aware of head injured. And it is still a major barrier that is still. The government being a political organization, their main criteria whether or not something is important is whether or not there is enough people making enough noise. So there is still a real major barrier, especially to weird things like head injuries. In a sense...with some of the more well identified diseases like cancer, heart trouble, muscular dystrophy, MS, or cystic fibrosis, which in a sense are entity diseases, or entity problems, MS isn't so much because it takes alot of forms, spina bifida, it is identifiable. There is a specific problem there, specific things that these people need. Head injury isn't that way at all. It is such a diverse group and to crack in there and let them know this is what it is. This is what its all about. Here are the things that are really required, that are really necessary. They're just too undefinable as a group. Look at any 10 people with head injuries.

I They are all so different.

P You're going to meet 50 different types of problems. And yet there is a real commonality in the whole thing, but governmment wants efficiency, wants to be able to identify and describe specifics as to what is going on. It just isn't there. One of the big goals or aims still has to be public awareness. Everybody knows there is such a thing as the MS society, o.k. It will take a few years but in time everyone whould know somewhere along the line that there is such a thing as NABIIS. That it is a common word like United Way or Catholic Social Services.

Appendix E

I How old are you?

P I'm 43.

I You are married? Number of children?

P Two.

I And their ages?

P Twenty-two and 21.

I And you're presently working outside the home?

P Yes.

I Were you working before the injury, before A. got injured?

P Yes.

I In the same area?

P No. No. We had our own business then. But that was too many hours. Like, that was 9:00 to 9:00, six days a week. The hours were always that long. And I used to bring the kids after school and they'd be with me at the shop. But then, after the accident, and A. came home...it was o.k. when he was in the hospital, the same things could happen. But then when he came home he wasn't well enough to go on the road with me or even be in the shop, because one day he threatened a little kid and the guy was going to sue us. And it was just really touchy to even have him around. And so, it looked like it was really necessary...I couldn't spend that many hours away, because A. wasn't safe to even be at home alone. We had another acreage then and the oil company road went through our yard. Well, Lord, he'd take chains after the people and everything. Wouldn't let them come in the yard. And he'd light fires in the field and all kinds of things. You just couldn't leave him. I couldn't afford to hire anybody to stay with him and we couldn't get any home services, or whatever you call it because we lived in the country. We weren't in the city or we weren't annexed, so we were really in a bind. Then a buyer came along and bought the acreage and we moved to the acreage where we are now. But...closer in. But then I had to sell the business too. Probably at a loss. Because you don't just sell something like that. I'm sure I didn't make any money off it anyway. And a friend of mine had been one of the first ... in the city and she'd asked me if I wanted to train. So it seemed good because now I can either work two or four nights a week, usually, or days and nights and earn a decent income, just to keep us going.

I What is your education level?

P Grade 12 and then business college.

I Two year college?

P No. I think it was a one year course.

I Did you make any use of any outside services? For example, any home care or DATS or anything?

P Oh, yeah. DATS for two months when A. went to school, which didn't work. The only things that we had were, whenever it got too rough at home because his medications would wear off, he'd go first off to the hospital and he started running away so he went to Alberta Hospital at Oliver. That is the only things that we ever had.

I So, those were the only services...even that wasn't a home service. You had to...

P No. There were no home services for us. And then the only reason we got DATS last year is because we got annexed. So it doubled our taxes. We got annexed so we got DATS for a couple of months. But that's it.

I How old is A.?

P He's 44.

I Do you remember the date of his accident?

P February, 10, 1977.

I Does A. work outside the home now?

P No.

I Has he tried?

P Yeah. One time he went to work at a... electronics, with his trade. He went to a small appliance repair shop downtown that took handicapped people but it didn't work. No. He figured they were running it all wrong and he wasn't...and on and on and on. He was too slow, too.

I Any kind of financial settlement received after the accident?

P Yeah, A. got $.

I Was that insurance?

I Yeah, insurance. Because he was a passenger in the car...the only reason we got that...I didn't know passengers weren't insured, you know. It really bothers me that you can be driving along and you feel that because you have insurance your passenger's insured eh. The only way a passenger gets insurance is if you can prove gross negligence. And we were extremely lucky. We had a surprise witness. A young fellow that actually had come to work for us. It was a friend of A.'s...his son had come to work for us a few days before, part time and happened to be going down the street behind him that night. And that's the only reason that they settled out of court and that they even wanted to settle. Because you have to prove gross negligence. Isn't that something?

I How often can you prove it?

P That's right. And when you carry insurance you feel you're insuring your passengers, don't you? Or I do. I still...why have it? It's terrible.

I When and how did you first learn about NABIIS?

P It was when I phoned the hospital to talk to this lady. I can't remember her name. And they told me that H. was the one that was looking after that area. They said something had already been started. Because I said I want to initiate something and they said something had been started.

I How long have you been a member?

P Since the very...well, February, I guess of '83.

I Did you consider your membership to be temporary or permanent?

P Oh, I think I probably felt it was going to be a long time because I could see what could happen, if you work hard.

I Why did you decide to join the group? You, personally.

P Me, personally? Because I felt there had to be a reason for A.'s accident and if that was helping other people, then I was going to put my best into it.

I How often do you attend meetings?

P Pretty well every meeting. Unless I'm working. Because I do have to earn a living too. But most times I can attend.

I Which ones? That would be the board meetings and the...

P ...and the executive meetings and the coffee houses.

P How are the board meetings and the executive meetings different?

P Oh, the general meetings. Pardon me, general meetings, board meetings, and coffee houses.

I How do you contribute? For you that's an odd question too. In every way you can. You are a board member. You do go to family support group. You do BINGOs. What am I leaving out?

P Well, I'm T.'s supervisor. I had to be that so we could get Access Canada's funds. I'm in daily contact with the office. So if there's any problems at all, I get them. And, well, I guess I help out in any area that comes up.

I Yes, you do.

P I almost feel like I have an executive director role sometimes, without the pay.

I I'd say that's pretty close.

P That's not quite true because I can't devote that amount of time but, gee.

I How has the group benefitted you?

P Well, I probably gained support through it by becoming involved with it. And you do learn as you talk with other people too. You learn more about...I suppose, how to deal with the type of handicap. But, you always know the rights and wrongs. And it's so much easier not to bother. You know that...you should get them to do things, but it's so much easier to do it yourself. Why even bother with the hassle, kind of thing, you know. So, you learn, and yet, you don't always follow everything you learn. It's a learning experience. And it gives you something else to think about. And not just feel sorry for yourself. Because there's other people out there with, maybe a lot worse problems than what you have.

I Did the group change the way you viewed the difficulties of head injuries? For you, A. was injured much before so you already had a few years to adjust to it. But did it change the way you viewed just the whole idea of head injury and that kind of thing?

P Probably, one of the things..I suppose it's one of the things H. was talking about...shame and guilt. I always thought I had to apologize for A.'s bad behavior. It embarrassed me if we were out somewhere and he... because he's not too nice to people. It's really, really odd. S. and I were talking about this and I think it's almost true. The area they excelled in most is the area they're worst in now. And A.'s job was PR. He was public relations for GE for all of Alberta. He was the service specialist. He had to settle a problem that no one else could deal with. That they couldn't...and PR was his big thing and he's just not so nice to people sometimes and it really bothers me because that's not him. And so it seemed like I was constantly apologizing for him which now I don't do so much anymore, because he has a handicap and maybe, I suppose, you're not even...he can even say it now. He couldn't even say it for years, that he was, that he has a head injury or brain injury or whatever. If a doctor asked him, how are you feeling, he'd say, oh, my leg isn't too bad today, or my back's really bad. He'd never deal with his problem. And so I suppose it's just easier to talk about. It's easier too, you know, knowing that...well I still sometimes apologize. I have to admit I

apologized to a poor girl the other day for something that wasn't called for. But people don't understand...they have no idea that maybe, because he walks and talks so well, if he looked at all like he was handicapped, then maybe they'd give him a chance.

I What was done by NABIIS to help you? NABIIS as a whole is a benefit, but is there anything specific, any one part of it. You're involved in so many different areas.

P Well, for me, I suppose it's just the accomplishment of seeing it grow. That was my whole thing in the very beginning. Seeing it grow into something that was going to be worth something. And not just something that just faded away because, you know, I've seen a lot of that happen too, where everybody's all terribly enthusiastic in the beginning and it just dies, because nobody's really willing to do that part to get it to really happen. And I was determined it was going to happen. And I think we're going to get there. And that's my main goal. And I worked really, really hard for the last two years towards an executive director,then I can just be a treasurer again. Well, I'll always be a volunteer, I know that. And I'll probably do a little more than a treasurer but it's just too many hours, the way it is. But I was willing to put out that two years to make it happen. And I hope it's only going to be those two years. I hope I don't have to be really putting in those kinds of hours. But I can just...I still have this vision and I hope the vision will happen so that we will be able to help get some things put in place. And who knows? Maybe. if we can get enough things put in place, maybe A. can even be helped yet too. Although they say up to 10 years is as far as they're going to be able to learn. But then T. had a gentleman in the office here the other day. And 32 years ago was his accident. Eighteen years he was off work. And he's just really well today.

I Any limitations to NABIIS?

P Oh, yeah, I think we went through some of those. And we aren't really..we're too busy to do the support area. We only have just a few real core of workers. I really put too much work on those people. I mean, I feel really badly when I call N. all the time but she's the only person that if I get in a bind and can't get something done during the day, she's the only one, and she's willing. And she's going to get to where she'll resent it soon too. I mean, that's what happens to people. If you can't get other people to really hlp, then those that are start to resent all the time they're putting in. Because I was getting resentful there for awhile. I know I was. And I still get...you do start to resent some of the time after awhile when you can hardly get away. Like, there's a lot of times that I could have gotten away and I can't because there's something happening with NABIIS. And sometimes you say, is it worth it? Are these people even going to appreciate what you're doing? There's just such a small core of people that do the work. What are some of the other limitations? Of course our lack of government funding - which I hope we're going to get.

I Any ways that you think it can be improved?

P I think with an executive director we're going to be a lot better off.

I Is that common for support groups to have an executive director?

P Yeah. The only ones that succeed are the ones with executive directors. They have that full-time person there, being able to carry out all the administrative duties and to try to zero in on any funding and be in contact with all the other services. Like, T. can't really do all this...get in with all the other services in the city. Like, SKILLS, we were really lucky that we happened in with them. But there are other service organizations out there that could be doing work for us, if we'd only zero in on them and give them the guidance to... you know, ask them if they will help our brain injured people. Not just the mentally retarded. See, who has the time? We just don't have the time as volunteers to go and do this every day, kind of thing. And T. doesn't have the expertise to do that. And he's actually kept very busy now just doing routine matters because it's become so big. It doesn't seem big but it is big in the sense that there's a lot of the routine, plus, we just have to grow in the other areas too. And I don't think that we can do it without an executive director. Somebody there every day to do that kind of thing.

I Just overlook the whole operation, basically.

P Yeah. To run it. It's a real management type thing.

I Have you received any other help as you were trying to work through the whole situation with A.'s injury? Any other professional help - psychologists, psychiatrists, social worker? Anybody help you get through with...

P Not as the family members at all. Whenever A. went to Alberta Hospital, Oliver, he had a psychiatrist, or at University Hospital. And I think they...he took D. in to talk to him once. Because it was D. that took the brunt of A.'s furor, I guess you call it. And he still...I'm sure he's still an angry young man. I can only remember them taking him in once.

I Mostly, then, they tend to ignore the family?

P Yeah. The family doesn't count. And, you know, the family's really affected. Boy. I say those kids really have to be commended. Because it was their decision that A. ended up staying at home.

I I'm sure it was tough.

P Yeah, I knew they had a future. And I didn't know about him. And if it was going to wreck their future then it wasn't really worth it. It's really, really hard decisions. Really tough.

I I haven't met D. But I met C. [illegible]he seems to be doing o.k.

P And D. is a person who won't talk. You'd never get him to...he won't talk about himself. He won't talk about...like, he's the one that really needed the help. And he won't talk about himself or how he feels.

I What role do the professionals fill now with respect to the group, at this point, now that it has been going almost three years? Are they still involved? Are they still helping out?

P Yeah. They're actually doing very well. Like, our BINGOs. My goodness. If we didn't have the professionals we wouldn't even be able to man our BINGOs. I don't know where the families are. That's pretty bad.

I Who goes out to the BINGOs?

P R. and H. every time. And they usually get a nurse or two to go with them. And then N. and her friends. If we didn't have those people, we wouldn't have BINGOs.

I Professionals are still actively involved in lots of ways.

P They certainly are. They want to see something. They know what happens to people once they get out there. And they know that they need...like R. said, I want to see nothing more in this world than to have what she calls...what did she call it...it was like a group home type thing, but a transitional home for these people because they have nowhere to go once they leave. If the family won't take them back and sometimes it's too hard on the families to take them back. And a lot of them, their families have abandoned them by the time they've even got to the Glenrose stage anyway. A lot of them...we've watched that.

I So do you find that they're over involved, not involved enough, or just right?

P I think we have really good cooperation from the professionals. They've been really good.

I And as you say, they are so aware of the need so they're right in there with you.

P Yeah, they really are. They've been really, really supportive. Too bad they didn't have more time.

I Yeah, that's common. They only have so much/energy. They also work all day.

P Yeah. They can only be involved in so many activities.

I A., have you been involved in any other self-help groups? Or is this the first and main one for you?

P No. This is the first. Anything else I've been involved in had really nothing to do with people. No, I had no idea what it even really meant. But I knew I wasn't goning to be good at the support part because...like, I couldn't go into a hospital and approach somebody. I know I couldn't. That's not me.

I Is anybody doing that? I've heard mixed things, that people are going up when they first have the injury and saying, we are NABIIS and if you need us, here we are. Other people say it's fallen through.

P No, I don't think...S. started writing a package, she had a package and she started writing a letter in the beginning when she'd see them in the paper, eh. And would just take it to the nursing station. We didn't want to become too pushy, kind of thing. But it didn't work. People werent' ready to hear anything at that point. And so I don't....unless, B. sometimes goes up to hospitals. And he's very good at that. I mean, he can pull that off and he can get away with it where most of us...he's very warm and genuine and whatever, and he knows what to say.

I So there's a little bit of that. Very little.

P I think just B. He's the only one I know that does that. But I know I'm not good in the support area, really.

I Giving it or getting it?

P Neither. Well, yeah, I'm willing to talk to people but they have to come to me. I'm not about to go to them. Isn't that awful?

I So you're there for them, but...

P See, I can sit at the coffee house and talk to people if they want to talk but, I don't know, it's not my thing, not really. I'd rather do more administrative type things. And that's not even what we're set up to do. But I guess you gain support from all this. I know you do. And you gain strength from it too, to carry on.

I Yes, definitely.

P Yeah.

I I don't have any other specific questions. Is there anything you'd like to add about basically the effect NABIIS had on you as a family member?

P I can't even think what you mean by that for sure.

I Have I covered everything or is there anything you'd like to add?

P I suppose one of the areas too that I forgot about in the limitations, is remembering the kids. That's very, very important. Somehow the kids always get left out. They don't think it ever effects the kids for some reason. Even other parents don't think it does. I can't understand that. When E. came in...she didn't understand much though.

I Would you like to see NABIIS have a special part for kids or another group for kids?

P Oh yeah. I think one day hopefully, if it ever happened that, boy we gotta get bigger facilities for our coffee houses. I can forsee that one would probably be for victims, one part would probably be for the spouse and the mother's and father's areas, and the other part would be for the children. If there was ever enough children that would want to become involved. But it has to effect even brothers and sisters, I would think, the same way as it does sons and daughters. Not as much, I wouldn't think. But still, it would have to effect them. Because they have some of the same, probably feeling guilty and all those things. Another thing I forgot too. We do need...we do need a counsellor, a professional person because I wouldn't even mind that. I mean if we had somebody that we could come and talk to sometimes. Because there's still a lot of questions you have in your mind, you know, sometimes you do feel guilty and you say to yourself, this is for the rest of my life, am I going to make it, do I want this for the rest of my life? There's a lot of questions like that. It would realy be nice to have a counsellor. I think that's an important part. Because we can't afford $50 an hour to go talk to these people.

I And even, they don't all understand. You need to choose someone pretty carefully.

P Yeah. Somebody that knows head injuries. It's a different field and we don't have many in Alberta. It's a real problem. Well, that probably does it. I can't think of anymore. There's probably a thousand things.